

Correspondence – Disabled

Folder Citation: Collection: Records of the 1976 Campaign Committee to Elect Jimmy Carter;
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http://www.jimmycarterlibrary.gov/library/findingaids/Carter-Mondale%20Campaign_1976.pdf

FROM THE DESK OF

Lyle Taylor

9-23-76

Dear Jimmy Carter,

I wonder if I might borrow
a few minutes away from
your busy schedule to look
at a national problem ---

Central Nervous System
Regeneration
Research Funding ---

Neuroscientists have made
some major breakthroughs
in the field of Regeneration
& Congress has responded,
(Senators Jackson & Magnuson
primarily) and added \$9.5
million to the H&W ^{Bill} that
is on President Ford's
desk now for signature.

FROM THE DESK OF

Lyle Taylor

(2)

We are talking about a cure that will help at least 200,000 paraplegics, 2 million stroke victims, 1/2 million Multiple Sclerosis, Dead Injury 3 Million, Mental Retardation 6 million, to name a few, & this is in the U.S. alone.

Leonard Frank, who took his son to Russia last year for enzyme treatments because he couldn't get them here, and I have been able to put three (3) Quadriplegics in front of President Ford

FROM THE DESK OF

Lyle Taylor

Since April '76 & he has told each one he would support a program (see white house correspondence enclosed) (pages 1 & 13).

My sources in D.C. indicate real concern that Ford will veto this H&W ^{bill} & yet we have not been able get him to call for a separate bill for this research problem.

I have been involved in spinal cord injury related problems for the past 2 1/2 years & have talked to a lot of paralyzed veterans

FROM THE DESK OF

Lyle Taylor

who tell me that the V.A. tells them that they have been working on this problem & yet I find their budget - as proposed (W.H. Correspondence, pages 7, 12, 13) is just a minor start which is conformed by a A.M.A. attitude that nerve cell regeneration is impossible, so forget it! (See John D. Chase letter to Sen. Hart, enclosed) And of course the Vets who really now understand the V.A. dogma are really mad because their lives could be a whole lot different if someone had followed up on what the scientists advocated

FROM THE DESK OF

Lyle Taylor

(4)

years ago. Nixon & Ford
have both been urged
desparately to put some
money into this (See Carmine
Clemente's letter - UCPA - enclosed)

Clemente's letter to Edith Greene
is intended to be hand carried
to Dole along with a letter
from Dr. Richard Sidman,
Harvard, which I have
yet to receive.

My letter (rather my wife's)
to Betty Ford (W.H. Comm.
pages 2-7) really covers the
subject on a fast look, but
I have additional data if
you would care for it.

FROM THE DESK OF

Lyle Taylor

(5)

I sincerely hope that you can find time to become involved in this critical issue.

Our time is flexible & we are more than willing to help you if we can. Our son Mike is not disfigured & makes a good appearance, as my wife & I honestly do. We have been to Europe & all over U.S. looking for answers & thus can tell quite a story if that would be of any help.

Regardless of how we

FROM THE DESK OF

Lyle Taylor

(6)

may help, please do not
hesitate to call at any
time.

May God Bless you &
each of us hope you will
be our next President.

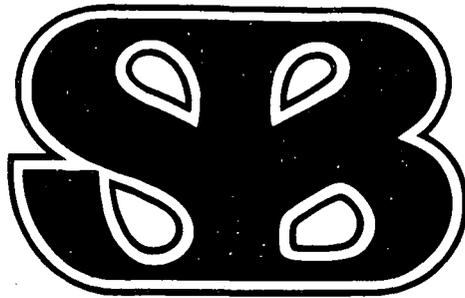
I thought your Playboy
interview was well done,
- even though we as Christians
believe in Jesus Christ, we
are still human & as such
can be tempted! People have
to know Jesus Christ to
understand!

with Warmest Regards,

Lyle

PHONE - 206-743-0887

LYLE G. TAYLOR
15515 52ND AVE
W.
EDMONDS, WA.
98010



Spina Bifida Association of America
P. O. Box 5568
Madison, Wisconsin 53705

July 1, 1976

DIRECTORS

President

Peggy Miezio
209 Shiloh Drive
Madison, Wisconsin 53705

Jimmy Carter
P.O. Box 1976
Atlanta, Georgia 30301

1st Vice President

Sandra Helton
9 Mountain Avenue
Montville, New Jersey 07045

Dear Mr. Carter,

2nd Vice President

Thomas Tapke
2141 Sylved Lane
Cincinnati, Ohio 45238

The members of the Spina Bifida Association of America, which is comprised of over 100 chapters throughout the country, are vitally interested in this election year in your views on the questions which directly affect the lives of children with disabilities and their families.

Secretary

Anna Tandy
104 Festone Avenue
New Castle, Delaware 19720

The organization's bimonthly publication, the SBAA PIPELINE (a sample is enclosed), is distributed to parents of children with spina bifida, their friends and relatives, adults with spina bifida, and professionals in medical, allied health, education and social service fields.

Mary Breukelman
Denver, Colorado

Esther Cummings
San Jose, California

Patricia Ekern
Naperville, Illinois

Barbara Metz
North Brunswick, New Jersey

Stanley Person
New York, New York

Elizabeth Pieper
Scotia, New York

Barbara Riley
Norristown, Pennsylvania

Jack Shurman
Woodmere, New York

Kent Smith
Elmhurst, Illinois

We would like to be able to include with our August/September issue your comments on plans to meet the needs of children with disabilities in areas such as: Federal support for educational programs for disabled children, Federal policy toward services and research in the field of disabilities, national health insurance benefits for people who are disabled, architectural barriers, alternatives to institutional living, and vocational rehabilitation.

Thank you for your attention to this request.

Treasurer

Wayne Killingsworth
1719 Imperial Crown
Houston, Texas 77043

Medical Advisory Committee

Anthony J. Raimondi, M.D.
Chairman

Nonprofit Organization

Sincerely,

Peggy Miezio
President

June 21, 1976

Dear Mr. Carter,

I am a quadraplegic who would like to know how you would support spinal injury research as president of the United States. I hope your support will be more than vocal as was John F. Kennedy's Commitment to spinal injury research which led to men walking on the moon. I would like very much to once again walk on this earth. Thank you.

Sincerely,

Robert K. McBride
Rt.2, Nora St.
Lisbon, Ct.

06351

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WILLIAM J. VAN NESS, CHIEF COUNSEL

United States Senate

COMMITTEE ON
INTERIOR AND INSULAR AFFAIRS
WASHINGTON, D.C. 20510

June 29, 1976

Mr. Lyle G. Taylor
15515 52nd Avenue West
Edmonds, WA 98020

Dear Mr. Taylor:

Thank you for your three follow-up letters on spinal cord regeneration since we visited in my office in late May.

The Appropriations Committee advises me that \$10 million has been added to the budget of the National Institute of Neurological and Communicative Disorders and Stroke, a significant portion of which will be used for spinal cord regeneration research and training.

I was happy to play a role in this budget increase.

With best wishes.

Sincerely yours,



Henry M. Jackson, U.S.S.

HMJ:ct

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WASHINGTON, D.C. 20510

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ARTHUR PANKOPF, JR., MINORITY COUNSEL

July 14th
1976

Mr. Lyle G. Taylor
15515 - 52nd Ave. West
Edmonds, Washington

Dear Mr. Taylor:

The Senate has now approved, 75 to 17, the health appropriations bill for Fiscal 1977 and I'm sure you will share my own pleasure at how this might help to expand our research efforts on regeneration, as well as spinal cord injuries.

Enclosed is a copy of our Report that was adopted by the Senate and you will find our recommendations pertaining to the National Institutes of Health starting on page 39 and for the Neurological Institute on pages 52-54. Our proposals would expand the funding available for stroke and nervous system trauma by \$5,797,000 -- an increase of over 30% in that activity -- and some \$4.3 million of that is to expand research on spinal cord injury-central nervous system regeneration areas where progress appears highest. That would, according to NINCDS officials, include nerve growth, nerve sprouting, the molecular mechanisms of transport of substances to the nerves, and the effects of hormones and of nerve growth factor on growth and regeneration in the central nervous system.

Overall, our recommendations for the NIH are \$491 above what the President had requested and about \$354 million greater than the current level of their expenditures. Although these are substantial amounts, it would provide a modest 14% increase in their activities which span the entire spectrum of diseases that plague man. While the bulk of the additional funding will help expand their immediate research capabilities, an equally important activity we would expand is the training of those who are capable of doing this highly sophisticated work. I hope that President Ford will ultimately agree with the Congress and approve this measure. I should certainly add that all that you have helped do and "spark" might well have a beneficial impact upon the White House and their decision in this matter.

I would also call your attention to our recommendations in respect to the programs of the Rehabilitation Services (pages 109-110). That increase of \$6 million would provide funds to better support the existing spinal cord injury system centers and to establish additional model spinal cord injury projects. That increase would also allow for expansion in areas of special emphasis such as rehabilitation engineering and international research.

Page Two

Mr. Taylor

14 July 1976

Once again, I do appreciate your personal concerns and efforts to see that greater attention by the public and public officials is drawn to these special needs in spinal cord injury and especially in the area of regeneration. I would hope that you would also help us to secure more adequate funding for all biomedical research, along with the training of health care delivery personnel and those future research scientists who will make those breakthroughs that we are all praying for.

With best regards, I remain

Sincerely,

A handwritten signature in cursive script that reads "Warren G. Magnuson". The signature is written in dark ink and is positioned above the typed name.

WARREN G. MAGNUSON, U. S. S.

WGM/wfr

Spartan Pa
June 13, 1976

Gov Jimmy Carter
P.O. Box 1976
Atlanta Ga

Governor Carter

I have heard statement
about welfare reforms
help for the elderly (which is
long overdue) but I have
heard nothing about and to
the disabled, why is this?

I am disabled with
multiple sclerosis and
I am having a difficult
time getting aid maybe
it's because I have no

2
Money to pay for said and
my main concern is
about medicare why hasn't
any candidate come out with
a statement about having
medicare pay 100% of the
hospital and doctor bills

I was taken by a hospital
for 28 over the deductible.

I put the hospital 88 dollars
to a hospital and I was to receive
a refund which never materialized
I also put the doctor 92
dollars but received no refund
from medicare. why is this?

I would like to know
this before November

when I sent in the bills.
 I had paid medical and
 I made a previous claim
 which is not so, I only
 used the medical once.

I did visit the Secretary
 State Hospital for a diabetes
 test but I paid for this
 with money of my own
 and medical was never
 mentioned.

As I never heard
 it is nothing more than a
 big rip off.

I might mention the
 diabetes test was five
 dollars

There was also a statement
in effect that the remaining money
would be added to next years
(following year) deductible

I asked what would happen
if I didn't make use of
medicare the following year
and everyone I asked suddenly
became mute

I am anxious to know
what you would do about Medicare
paying 80% of hospital and
doctor bills

Sincerely yours
Joseph G. Robish

JOSEPH G. ROBISH
183 WILBUR ST
SCRANTON PA
18508

Alice Fioritto

President of Am Council
of Citizens Coalition
of People with Disabilities

Organization

0 202 966 0972

41 202 686 0436

Wants answer to what is
doing with disabilities

refer to Barbara Blum

or Sandra Butler

Room 309, 1345 Connecticut Avenue, N.W. • (202) 785-4265
Washington, D.C. 20036



American
Coalition of
Citizens with
Disabilities
Inc.

August 20, 1976

Ms. Mary King
Mary King Associates
2000 P Street, N.W.
Washington, D.C. 20036

Dear Mary:

I was pleased to have our brief meeting a week or so ago, and I look forward to working with you, Louise, and the other members of the campaign staff.

Presently, I am contacting individuals involved in disability throughout the country obtaining their consent to participate in various phases of the campaign. Some will be involved in a type of speakers bureau, others will be available as consultants to local and state staffs, and others will be involved with the Democratic Committee in the "Get Out the Vote" campaign.

In spite of these efforts, I and many of us who are interested still feel that we are functioning without acceptance and direction from the Carter campaign people. It is most unfortunate that even in this effort people with disabilities must fight to exercise their rights to be involved to share and participate. However, we are familiar with this stance, and because we believe in our principle and rights, we will continue.

Attached is an article from the New York Times of August 19, 1976 which gives me grave concern and which can have a negative effect on the campaign efforts. Disabled people and parents of disabled children have worked hard for many years to receive good public education and to be mainstreamed. Mr. Shanker, one of the first supporters of Governor Carter in the attached article is supporting denial of the rights of disabled children for equal education, which, by the way, is illegal based on Section 504 of the Rehabilitation Act of 1973.

Many parents, disabled persons and their families, putting all these facts together, will have a considerable problem supporting Governor Carter unless he comes out with some statement to clarify

his position. Being fully aware of the power and strength of the U.F.T., I do believe that a satisfactory position for Mr. Carter can be developed. Since this article appeared, I have received several phone calls from across the country inquiring about Governor Carter's position. I find it difficult to respond.

This matter is brought to your attention with the expectation, and interest, that you will take immediate action.

Sincerely,

Eunice Fiorito

Eunice Fiorito
President
AMERICAN COALITION OF CITIZENS
WITH DISABILITIES

EF/ljs

cc: Joe Duffy
Bill Johnston
Mark Dayton
Louise Weiner

Teachers Weigh Limit on Number of Handicapped Pupils Per Class

By GENE L. MAEROFF

Special to The New York Times

BAL HARBOUR, Fla., Aug. 18

—The trend toward integrating handicapped children into regular classrooms is a cause for concern among the nation's elementary and secondary school teachers.

The practice, known as mainstreaming, is becoming an issue in many school districts as teachers complain that they are being given added responsibilities without adequate preparation or commensurate relief from their usual teaching loads.

Controversy over the implementation of mainstreaming is spreading at a time when the schools are being forced by court decisions and legislation to admit tens of thousands of handicapped children who previously were denied a right to public education.

Teacher organizations around the country have begun seeking some control over the conditions under which mainstreaming occurs. A reflection of their concern is a resolution being considered here at the annual meeting this week of the American Federation of Teachers.

Limit Per Class

The 470,000-member organization is expected to resolve that there be "educationally sound reductions in class size with up to but no more than two handicapped students in a regular class."

Teacher organizations in Pittsburgh, Detroit and Chicago have already incorporated limits on mainstreaming into their labor contracts, and in New York and elsewhere teachers would like to get similar agreements from their school boards.

"Some school administrators see mainstreaming primarily as

a way to cut costs," states a special report distributed to the 2,800 delegates at the federation's convention at the Americana Hotel. "In these cases, all or most special-education students have been placed in regular classrooms with no provisions for support services, individualized instruction or teacher and student preparation."

While teachers maintain that there is great potential for abuse in the implementation of mainstreaming, they say that they generally endorse the concept itself.

Mainstreaming is viewed as an improvement over the approach used until now in which the handicapped have been segregated into separate classes with little or no contact with so-called normal students.

How Program Works

As the word implies, mainstreaming involves putting handicapped students into as many parts of the regular program as each youngster's physical, emotional or mental condition allows.

Art, music, industrial arts and physical education tend to be the first areas in which the handicapped join other students. But some of the youngsters are also able, often with special support services, to take some or all of academic courses as well.

It is acknowledged by almost all educators that the most severely handicapped youngsters may not be able to join any portion of the mainstream program.

Teachers say that for mainstreaming to be successful there must be training for the teachers who are suddenly expected to include handicapped students in their classes.

"There is an innate fear of

mainstreaming in many teachers because they don't understand the disabilities of the students," said Ann-Marie Ruder, a teacher of the handicapped in Detroit.

"For instance," Miss Ruder continued, "there are four kinds of seizures and how does the average teacher know that a petit mal seizure can be virtually ignored while a psychomotor seizure means rearranging the furniture so that the child does not get hurt."

Assignment of Pupils

Many educators feel that the decision as to which handicapped student should be mainstreamed should rest with the special-education teachers and that then each regular teacher should have the option of whether or not to accept the handicapped child into the class.

"The average teacher is trained to teach only the average child," said Sol Levine, a vice president of New York City's United Federation of Teachers. "No teacher who is unwilling should have to accept a mainstream child."

A resolution adopted this year by the 215,000-member New York State United Teachers, the largest state organization within the American Federation of Teachers, calls for a moratorium on mainstreaming unless various preconditions are met to protect teacher and student rights.

The possibility of having more handicapped students than they can handle assigned to their classes worries many teachers.

In the debate that led to the resolution calling for restricting enrollment to no more than two handicapped youngsters, the regular class, Joe Moren, a high school history teacher in Hib-

bing, Minn., cited his experience.

"I like the way this resolution is written," he said. "Two is a good definite number. I had a blind girl and a boy in a wheelchair in a class of 30 this year and I thought that was enough."

Moreover, teachers contend that if regular classes include handicapped youngsters in each class should be smaller than those without any handicapped students.

"I voluntarily accepted two children with serious difficulties into a class that already had 36 students," said Pat Stringer, an elementary school teacher in Los Angeles.

"It made for a very difficult, long and tiring day," Mrs. Springer said. "It made me short-tempered and less able to

find time to work with the other children."

A provision in the contract of the Pittsburgh Federation of Teachers specifically bans the assignment of more than six handicapped students to regular classes. In addition, total class enrollment of all pupils is limited to 30 in elementary school, 32 in middle school and 33 in high school.

Albert Shanker, the president of both the national teachers federation and its New York City local unit, said that he expected the details on the implementation of mainstreaming to become a major issue in the negotiation of teacher contracts.

FRESH IDEA
AID THE FRESH AIR FUND.



EMPLOY THE HANDICAPPED

COMMITTEES OF METROPOLITAN DADE COUNTY • 2501 CORAL WAY, MIAMI, FLORIDA 33145 • 579-5716

August 6, 1976

The Honorable James Carter
Post Office Box 1976
Atlanta, Georgia 30301

Dear Mr. Carter:

We must alert you. The disabled are the nation's largest minority, yet they frequently get overlooked in official thinking and left out of public planning. Most recently, concern, interest and planning for the disabled were omitted from the Democratic National platform.

Thus we call to your attention a position paper, *The Challenge to America's Third Century*, which will be of value to you in understanding the views, perspective and problems of the disabled. This is not a document proposing special privilege. Instead, it is based on pride, dignity, equity and participation in society. We ask you to read the document and evaluate its principles and purposes for inclusion in your planning and public statements.

Moreover, we invite you to show immediate leadership in behalf of the disabled by becoming an "original signer" of this "Declaration of Independence" for the Disabled. Please do so by affixing your signature to the blank space on the back of the document and encouraging others to sign along with you. The signed document is to be returned to us.

Yours sincerely,

Daniel S. Holder

FHR:mcc

Enclosure

20 OCT REC'D

SC.

Telegram

Mrs. Isabel B. Caudell
P.O. Drawer 577
Meyersdale, S.C. 29945

October 15, 1976

gent

The Honorable James Carter
Plains, Georgia

~~NOT Press~~ ^{we} should ^{think}
for ^{it} - something
to ^{help} something
x5 075

Sir:

As you are aware, the President has proclaimed the month of November as National Mental Retardation Month. We are so fortunate to be born without the handicap so many of our children have and we can do something to help them cope in this "wrong size world" of ours.

I am a teacher at one of South Carolina's many Headstart Adult Activity Centers for the Mentally Retarded. I have learned through patience and understanding that these young people need us to love them and even more, need the public to be aware of their basic needs — and there are so many needs.

I am certain you are nearly plagued daily with requests from hundreds of people asking for some sort of help. What I'm asking of you is only local, public recognition of the Beaufort-Jasper County's November 4th Open House to raise funds for our mentally retarded children's day care center — Beaufort Adult Activity Center and the Waddell Day Care Center.

We are broadcasting live, via WSIB radio all day as a telethon for this project, and are soliciting sales of raffle tickets (for a silver tea set) to buy what we need for these kids. We are small, but our need is so great.

My request is to merely acknowledge the drive by telegram or similar media, to arrive at BAAC (1810 Boundary St. Beaufort, S.C.) during broadcast hours (9:30-12:00) to be read over the air. In the message, if you would be pleased to - give the listeners something to grasp hold of about their role in aiding these M.R.'s to a better life - perhaps a challenge to them as Americans; to show love for their fellow citizens less fortunate than they - and donate their time or funds - or both - for these great kids; their education, training and the chance for understanding dignity and self confidence they deserve.

Give these people that last good feeling about why they did vote for you during the upcoming Presidential Elections.

Please acknowledge receipt of this letter to me - many wonderful kids are counting on you.

Respectfully,

Isabel B. Caudill

P.O. Drawer 577

Yemassee, S.C.

29945

Greater Los Angeles Council on Deafness, Inc.

621 SOUTH VIRGIL AVENUE, LOS ANGELES, CALIFORNIA 90005

TELEPHONE Voice and TTY (213) 383-2220

FROM SAN FERNANDO VALLEY: 780-2200

FROM SAN GABRIEL VALLEY: 579-4474

A non-profit agency dedicated to the social, economic, educational and cultural welfare of the hearing impaired through member organizations.

T. Carter
Rept
August 12, 1976

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Club of the Deaf
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Temple Beth Solomon
of the Deaf
West Valley School,
Hearing Impaired Parent Group

Jimmy Carter
Plains, Georgia

Dear Jimmy,

I am writing to you because of a newspaper article I recently read concerning programs you plan to implement when you are elected President of the United States.

The Greater Los Angeles Council on Deafness, Inc. (GLAD), which is an umbrella organization of many deaf and hearing organizations interested in promoting the cause of deafness, has vital interest in your candidacy because of the impact that your future programs may have on hearing-impaired people throughout the nation.

The deaf have suffered suppression throughout the 200-year-long history of our country due to their communicative difficulties. They now realize that they are a sleeping giant, suddenly awakening to ponder over what their rights are in all areas of life.

The deaf no longer feel that administrators who govern their affairs are qualified to do so! These administrators in all levels of public and private agencies depend on submission of our people for their continued existence and power.

This letter, therefore, requests that you consult the deaf, themselves, in matters relating to their interests. It is reliably reported by the United States Department of Health that one out of fifteen persons is hearing-impaired, and that these 14,000,000 are demanding that their voices be heard!

The average deaf person is under-educated, under-employed and earns well below the average non-handicapped population, although his intelligence and manual dexterity are not impaired. Extremely few are administrators, although they are capable of administering. One reason that we have this situation is that many non-handicapped people are trained with rehabilitation monies intended

for the deaf. This creates more competition for jobs, especially those positions related to deafness.

Some examples of how deaf people are relegated to second-class citizenship are: They do not have equal access to the telephone, although expensive teletypewriter-coupler equipment has been in use for a decade by more affluent deaf persons. This TTY equipment, as it is referred to, enables us to telephone others similarly equipped and costs from \$350 to \$1000. We are trying to persuade the phone companies to mass produce this equipment to a point where it would cost approximately the same as the telephone provided to regular customers. Another example of inequality is that in dealing with various agencies, deaf people are supposed to communicate with them without interpreters who are fluent in the use of sign language.

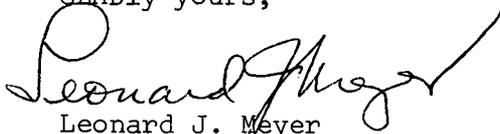
Still another example is that although a decoder has been developed which deaf people could purchase to make possible captioned television programs, nothing is being done in this area of communication, even though the hearing-impaired form a large enough constituency to patronize advertisers. We get nothing from televised news, although we are taxpayers, too. We want first-class citizenship!

Consulting with just any organization on deafness will not do. Some are self-serving and sidestep real issues. For example, there are four deaf people on the President's Committee on Employment of the Handicapped. All are from the Washington, D.C. area and none from the West Coast. To top that situation, the hearing-impaired are under-represented on the committee because they constitute the largest percentage of the handicapped population.

Please let us know about your appearances in Los Angeles so that we can arrange for interpreters to enable us to listen to your speeches. What a boon it would be to the deaf if you employed interpreters on all of your televised political appearances prior the November Election and at all of the presidential appearances, also!

Thanks for your careful consideration of our letter.

GLADly yours,


Leonard J. Meyer
President

LJM:mk

September 29, 1976

Mr. Leonard J. Meyer, President
Greater Los Angeles Counsel on Deafness, Inc.
621 South Virgel Ave.
Los Angeles, CA 90005

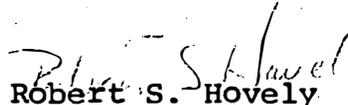
Dear Mr. Meyer:

Thank you for your letter of August 12, 1976. I apologize for taking so long to reply. Governor Carter has referred it to me as I am handling health care issues on the staff level during the campaign.

Governor Carter shares your concern about people who are discriminated against because they are deaf. I am enclosing a copy of his position paper on Americans with disabilities. I would be pleased to have your reaction to the material. I am forwarding a copy of this letter to Ms. Janet Oliver of the Campaign Manager's Office, so that she can contact you with information about our Advisory Committee for Disabled Americans.

Thank you for your thoughts and interest.

Sincerely,


Robert S. Hovely
Health Issues Coordinator
National Issues and Policies

cc: Janet Oliver
Enc.

Jimmy Carter Presidential Campaign

MEMORANDUM

TO: Stu Eisenstadt
FROM: Judy Lipshutz 
SUBJECT: Disabilities Sub-Task Force
DATE: July 28, 1976

Just a couple of points for your information:

We have attained a list of organizations and individuals concerned with or consisting of the handicapped. We plan to send the speech to a selected group of these persons and or their organizations after it is given. A member of the National Paraplegia Foundation, Dave Williamson, who has contributed his thoughts to the Task force contributed a substantial set of about 800 mailing labels for our use in this mailing.

Williamson also suggests that we use the speech as a news release

to send to periodicals and publications to be used in issues released prior to November.

By the way, interest in this area has been tremendous in both quality and quantity from disabled citizens. Our active group here is also beginning to put together a "get out the vote" effort.

Henry Butts

July 29, 1976

Ms. Mary E. King
2000 P. Street
Northwest Suite 415
Washington, DC 20036

Dear Ms. King,

Dr. Fred Fay of Boston has forwarded to me your statement by Governor Carter relative to the physically handicapped. Dr. Fay is a member of the American Congress of Rehabilitation Medicine of which I am President. I have conveyed some thoughts to him which he may have passed on to you. The Congress incidentally is the largest organization of professionals involved in the care and consideration of the physically handicapped - and the Rehabilitation Institute of Chicago is the largest facility for the treatment of the physically handicapped in the country; so, you can imagine that these matters conveyed in the "disability speech" concern me tremendously.

I have several observations;

1. Involving "consumers" (patients) in devising plans, policy and procedures in the process of rehabilitation and establishing community impact is essential and been a long time in appearing on the horizon. The handicapped individuals themselves have been slow in becoming a activist and expressing themselves. With the advent of their greater involvement I have found the health professionals and bureaucrats and politicians have been slow in listening acutely enough to this important segment of people.

To help alter this situation and to insist on more community concern is my stated major goal in this one year term as president of the American Congress of Rehabilitation Medicine. It is highly significant that Governor Carter in his "speech" recognizes his ability to listen to the consumers voice so pointedly.

2. Most people want to hear the actual numbers of how many people who are actually handicapped now or at some given moment. These

Ms. Mary E. King
July 29, 1976
Page 2

numbers are indeed considerably- or at least are considered so by most people. I personally like to stress too that a handicapped will probably exist in every individual (who does not happen to die by sudden death) and that now essential every family is touched in some way by a handicapp

3. I believe very strongly in the concept of Rehabilitation to employment. One reason that this is not accomplished as well as it might be is that those of us trying to accomplish this are not experienced enough "business". In the minds of business men, vocational counselors, social workers and physicians are "do gooders" - some good, some bad - but largely remote from reality. Here at the Rehabilitation Institute of Chicago we have placement people hired out of business and who are able to talk language of industry. Since employing people of this category our placement results are appreciably improved. Business must be more involved in Rehabilitation process and the planning. There are also very significant side effects to this in that when community people become involved in the employment of someone who is handicapped their attitudes are likely to change and they are likely to consider other means of being useful to this "cause".

Also, in talking only about jobs one is leaving out a category of the handicapped who will never be work capable, but who have terrible fears of being discarded altogether. Obviously, they need consideration, as well relative to enhancing their quality of life.

4. Speaking to the matter of accessibility is extremely important. All too often we get people jobs in buildings that will not allow access for handicapped persons. There are great strides made, and here in Chicago and Illinois for instance we have achieved legislation (as in Georgia) and Mayor Daley himself has an active and personal interest in this. We have at the Rehabilitation Institute of Chicaggoa unit called Access Chicago which has had great impact. I have talked to Nancy Hanks who through Jamie Wyeth has had a resolution passed in the National Endowment of the Arts relative to accessibility in cultural facilities and she has recently at my suggestion hired someone full time at the endowment to deal with problems of the handicapped.

5. Meticulous consideration must be given to the rehabilitation services administration in HEW. Historically that agency has had more impact than any group in the world toward helping physically handicapped people. It is a small economical effective agency (or was origiaally) developed by a brilliant bureaucrat, Mary Switzer. It has

Ms. Mary E. King

July 29, 1976

Page 3

been allowed to languish, a fact which should be in the highest order of disgraced to federal government. It needs shrewd and dedicated management and leadership.

6. Housing for physically handicapped is a major problem. Though Access Chicago is trying to alleviate this factor here, it is an overwhelming struggle. Certainly I would think that HUD could do more.

7. Attitude. The subtleties of attacking this problem is complex, but should be addressed. I feel Americans at this time tend to be so repressive of the fact that we are indeed an aging population with millions of physically handicapped people - increasing in number yearly. In trying to suppress the presence of this reality, people tend to reject the handicap by avoidance. The country is after all based on the success of a coalition of different nationalities and types of people. Surely there can be strength and consciously including the handicapped in the main stream of American life.

It is a reassuring and inspiring fact that Governor Carter is showing such sensitive concern regarding these issues.

Henry B. Betts, M. D.
Professor and Chairman

Executive Vice President/Medical Director
Rehabilitation Institute of Chicago

NEW YORK CITIZENS FOR CARTER/MONDALE

16th Floor, 730 Fifth Avenue, New York, New York 10019

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Campaign Director
Gerard F. Doherty

Campaign Coordinator
Bartle Bull

Fiscal Officer
Jonathan Stein

September 13, 1976

MEMORANDUM

To Janet Oliver, Dave Webb, Bob Havelly, Eunice Fiorito
FROM: L. Allison, J. Davis
RE: President Ford Committee info re handicapped people

Enclosed is information sent to a local NYS agency regarding the Ford position on disability etc. It is fairly broad material much of which is pre Convention pre-campaign and in my opinion is not as well developed as even our initial stuff. I suggest that we begin to collect this material from as many sources as possible to assist us in formulating a plan of attack via the debates, speakers bureaus and subsequent written material

P.S. Please keep addressee's name Confidential

Upstate Headquarters: 112 Powers Building, Rochester, New York 14614 • 716/325-3420

Upstate Campaign Director: Susan Holloran

New York Citizens for Carter/Mondale has been authorized as a name for the 1976 Democratic Presidential Campaign Committee, Inc. in New York State

Paid for and authorized by 1976 Democratic Presidential Campaign Committee, Inc.

HANDICAPPED

Richard Rosenthal

~~60 WEST 90TH STREET~~

~~NEW YORK CITY 10023~~

~~(212) 302-9001~~

817 West End Avenue
New York N.Y. 10025
212-8661232

Bill J

August 17, 1976

Stuart Eizenstat
Issues and Policy Division
Jimmy Carter Presidential Campaign
P.O. Box 1976
Atlanta, Ga. 30301

Dear Mr. Eizenstat,

I've ~~was~~ had a hearing loss for about 30 years, from gunfire noise in World War II, and been a journalist since 1960. A few years ago, I put the two together to try to find a good hearing aid for myself & and to try to find out why aids provided such a poor quality of sound reproduction during our time of remarkable electronic achievements.

With virtually no knowledge of electronics, without even the ability to hook up a hi fi, I assembled and have used regularly for three years, what is probably the best hearing aid in the United States. It costs less than conventional aids. I have a shotgun microphone, the ability to change microphone heads easily, separate bass and treble controls and a frequency range of about 200 to 13,000 cycles, all features that provide far better clarity and speech comprehension than aids on the market. It serves me well at writing assignments, at movies and as foreman of a grand jury. I obtained it simply by going to a good electronics store and buying a good microphone, amplifier and light earphone.

The fact that a better, wearable hearing aid is so easily concocted and that so few people do it is a problem in itself and a symptom of many others affecting rehabilitation of the handicapped.

The accepted reason for the inadequacies of aids is that everyone with a hearing defect is so embarrassed by it he'd rather hide the fact than hear better. This view has been accepted explicitly and implicitly by each of the many government and consumer groups that has tried to cope with the hearing aid problem. Going back to 1962, these include the FTC, FDA, VA, Nader's

Retired Professional Action Group, two Senate Hearings chaired by Senator Church and one by Senator Kefauver, not to mention just about every state ~~leg~~ legislature. All segments of the hearing health field, no matter ~~h~~ how much they battle on other matters, agree that concealment must be a priority in hearing aid design, even if their performance suffer substantially as a result.

However, when one stops to consider the plausibility of 15 million present and potential hearing aid users, with their varying occupations, lifestyles and degrees and origins of loss, all being so embarrassed they'd rather sacrifice success and pleasure for an insufficiency, inflexible and ugly little sound system, the embarrassment ~~w~~ explanation becomes a ridiculous exaggeration. Add to this the fact that spectacles have become fashion accessories, as in a way has conspicuous audio equipment on television performers, and it's clear that the embarrassment that does exist can be overcome.

Another contention that retards quality and diversity in hearing aids is that people with a hearing loss can only learn to adjust to one amplification ~~system~~ system at a time. This is also impossible. We use alternatives all the time, as a matter of course, e.g. amplifiers in telephone headsets, earphones ~~with~~ with television and hi fi.

The matter requires ~~a~~ fresh consideration and approach. If you or other representative of Governor Carter's staff would like to explore this further, and possible ways of improving the situation rapidly and inexpensively, please feel free to call me. Meanwhile, I enclose an article from the New York Times Op Ed page, written in 1973 just before I acquired my aid, and the cover of my book published this January.

Sincerely,



Richard Rosenthal

The Better to Hear



The Bettmann Archive

By Richard Rosenthal

Incredible as it may seem, in a day when electronic miracles have become commonplace—when man can eavesdrop on outer space and ocean bottoms—the design, marketing and discussion of hearing aids is more superstition-ridden than in the days of ancient Greece when slaves and citizens went about with punctured seashells strapped over their ears.

What kind of service would you expect from a stove, cigarette, contraceptive, telephone, typewriter, tractor or any other appliance that was made first to be tiny and hidden and only then to serve its stated purpose?

That's how hearing aids are made—to be hidden! That's why 15 million Americans with impaired hearing can hear astronauts broadcasting from the moon better than a spouse talking from across a breakfast table. Despite the skill of American technology, hearing aids are feeble, frustrating implements with the sound quality of a cheap loudspeaker and the endurance of a child's gimcrack.

Hearing aids are inadequate because concealment, more than better hearing, is the goal of their design. Hearing

aids are not thought out to aid hearing but to cower surreptitiously—secreted and unknown—in or behind an ear or pair of glasses or under clothes. Key components aren't big enough to perform well. Tone quality is poor. Sounds are raspy and muddled. And the constricted space precludes reliable quality control and servicing.

No other type of hearing aid exists, unless it is a medical or military secret. I am eager and ready to wear an effective, manageable hearing aid, however conspicuous. I will gladly go about with an aid of about three pounds on my head, eight pounds on my chest or fifteen pounds on my back to approximate the sound quality of my \$30 transistor radio.

I have told this to executives of hearing aid companies. They smile benignly and reply that I wouldn't really wear it. No one would, they say.

I have also told this to audiologists and otolaryngologists (ear, nose and throat specialists). They smile earnestly and say the same thing. People won't wear a hearing aid that looks like a hearing aid, no matter what it might do for their hearing.

Nonsense! Large hearing aids are now in fashion. Astronauts, radar operators, television personalities, models

in cigarette commercials, beachcombers and teen-agers all enhance their images with conspicuous headsets—with hearing aids. Why not the hard-of-hearing? Smallness and concealment are a recent idea. For thousands of years, until the transistor appeared in the 1950's, people used large, ornate hearing aids—ear trumpets, tubes, horns, metal discs, brass resonators.

I do not suggest that the hearing-aid industry produce appliances as cumbersome as brass resonators. I am suggesting what many hearing-aid engineers and designers concede privately, that were it not for current proscriptions of smallness, aids with much better fidelity, range and life-span could be designed in comfortable, attractive packages that the hard of hearing would love to wear.

The fount of resistance, I am convinced, is less with us than with the professional and business people that serve us. Almost all I have met unquestioningly accept the canard that we would rather conceal than conquer our disability. Manufacturers in this small industry (some forty companies with annual hearing-aid sales of about \$70 million) are keyed to making small aids for a small market, dealers to selling concealment more than hearing. Agencies and audiologists are preoccupied with succoring and processing the downtrodden. Otolaryngologists concentrate on treating afflictions that lend themselves to medical or surgical intervention, while blinking at patients whose only recourse is electronic amplification.

Small wonder hearing aids aren't what they could be. Small wonder we are "embarrassed" by them.

It is time America devoted common sense and genius to producing, marketing and fitting hearing aids for the millions who need and want them. Scientists, electronics engineers, politicians, component makers and the prestigious names in computers and consumer electronics can all profit from such an undertaking, as can the deafness professionals and merchants who question the conventional wisdom of their field.

The technological know-how exists. The fashion climate is right. And I want to hear.

Richard Rosenthal, a writer and an Oxford graduate, suffered damage to his hearing in military service in World War II. He is working on a consumer book for the hard-of-hearing.

Rosenthal

The Hearing Loss Handbook

**The
Hearing
LOSS
Handbook**

HOW TO
COPE WITH
HEARING LOSS,
HEARING AID
DEALERS AND THE
MEDICAL-
REHABILITATIVE
ESTABLISHMENT.

**Richard
Rosenthal**

St. Martin's

**The
Hearing
LOSS
Handbook**

tells you -

What hearing loss is

How to handle doctors and audiologists (and what you should *not* tell a rehabilitator)

Who gets to see your hearing center file (anybody who wants to, except you!)

How much dealers make on each hearing aid sale (and how you can save up to \$150 on a hearing aid—or even make your own!)

Why fund-raising tactics result in a patronizing attitude toward the hearing impaired

What audiograms can—and can't—tell you

Why you should bargain for lower fees even with "non-profit" organizations

The truth about acupuncture and deafness

and much, much more!

NEW YORK CITIZENS COMMITTEE FOR JIMMY CARTER

Suite 307, 730 Fifth Avenue, New York, New York 10019
212/757-3010

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Margaret Costanza
William J. vanden Heuvel

Bill

Campaign Director
Bartle Bull

Deputy Director
Howard Teich

August 10, 1976

MEMO:

To: Stu Eizenstat

From: Bill vanden Heuvel

The enclosed material was sent to me by Dr. Howard Rusk, the founder and director of the Institute of Rehabilitation Medicine. You undoubtedly know Dr. Rusk, at least by reputation. He is a pioneer in the field of medical rehabilitation and has won international renown for his contributions in the field.

As an old friend, he called me to see what he could do to help in the Carter campaign. I would suggest that Harry Schwartz invite him to be a member of the Medical Task Force. I would think that your associates in the Issues area could also use him as an important resource person.

I think it is important that someone contact Dr. Rusk so that he is aware that Atlanta has been informed of his interest.

BM

Upstate Headquarters: 112 Powers Building, Rochester, New York 14614 • 716/325-3420

Upstate Campaign Director: Susan Holloran

 96



NEW YORK UNIVERSITY MEDICAL CENTER

Institute of Rehabilitation Medicine
400 EAST 34TH STREET, NEW YORK, N.Y. 10016
AREA 212 679-3200
CABLE ADDRESS: NYU MEDIC

July 29, 1976

SUPPORT OF REHABILITATION AND PROGRAMS FOR THE HANDICAPPED

There are presently an estimated 50 million people with some form of serious functional impairment affecting their ability to participate in activities of ordinary living. According to the 1970 census, about 12 million people in the age groups 18 to 64 had total or partial work disabilities resulting in lost productivity to society as well as lost wages and activity for the individual. Of the 50 to 60 million disabled individuals with serious disabilities, about 9 million are arthritic, 5 million are functionally limited by heart ailment, 8 million have impairments of the back or spine, and 9 million have vision impairment including total blindness. The major killing diseases - heart, cancer, strokes and diabetes - often leave individuals seriously impaired through amputation or neurological damage. For example, there are some 440 thousand new cases of stroke detected each year.

Rehabilitation is a major medical and vocational program designed to eliminate or substantially reduce physical impairment thus enabling individuals to attain self sufficiency where possible through competitive employment or to achieve maximal functional independence. Through rehabilitation, the disabled receive services aimed at physical restoration, social adjustment and vocational training. The focus is on jobs and human productivity; on goals that are rewarding both to society through increased productivity, lesser unemployment and more taxes paid, and to individuals through their feeling of participation in work. Unfortunately, the rehabilitation program is not reaching even the tip of the iceberg despite its proven effectiveness and cost benefit ratio. Only 362 thousand individuals will be rehabilitated through the federal - state vocational rehabilitation program this year, according to HEW estimates. This is a high percentage of those served in one year, but is resolving only a minor part of the problem. Yet, for every dollar invested in rehabilitation, studies have shown a 9 to 1 return on investment due to the reduced welfare payments and increased productivity and tax revenue.

A study of spinal cord injured shows lifetime cost savings from rehabilitation of 60 thousand dollars in reduced medical and nursing home care. Another study done for HEW shows that comprehensive rehabilitation improves functional ability at discharge of severely disabled patients by about 100% for stroke, arthritic and spinal cord injured patients.

While the federal laws provide much in the way of rehabilitation programs that help the handicapped and disabled become workers and self sufficient, these laws have not been executed effectively, nor supported by the recent administration. The Rehabilitation Act of 1973 contains the major rehabilitation services program, rehabilitation professional training and research, and support of rehabilitation facilities and special centers such as centers to serve the spinal cord injured and the deaf. The Rehabilitation Act of 1973 also contains major new legal rights for the handicapped - rights to a barrier free environment including housing and transportation, and rights to be treated equally in education and employment. This Act was vetoed twice before it became law and recent amendments extending it were vetoed again. The Democratic Congress persisted and eventually the 1973 Act became law and the extension became law. The non support of this important legislation became non execution of the law. For about 18 months, the Rehabilitation Services Administration was without a Commissioner from late in 1972 until April 1974. Regulations for the implementation of the rehabilitation services program were not finalized until about 18 months after the law became effective in April of 1973. Regulations regarding the provision establishing the rights of handicapped individuals not to be discriminated against in employment, education or other areas of federal support, have not yet been finalized after more than three years. In addition, appropriations for rehabilitation programs have been vetoed every year since 1973. Presidential budget for these years attempted to reduce and in some cases phase out or eliminate services, training, and research programs.

It is time for a Democratic Presidential candidate and President to take on the cause of disabled people and the rehabilitation program, both in the name of humanity and to assure effective, productive use of federal funds. The disabled want to work and function without dependence. It benefits government to enable them to do so since welfare and disability support will be lessened and these individuals will pay taxes into the federal treasury.

The next President should fully support the programs of the Rehabilitation Act of 1973 through: 1) Good appointment of effective Administrator; 2) adequate financial support for the vocational rehabilitation program, including research and training; and 3) support of coverage of comprehensive medical rehabilitation under National Health Insurance, and timely and broad coverage for all disabled people under National Health Insurance.

STATEMENT OF BYRON B. HAMILTON, M.D., Ph.D.

FOR

AMERICAN CONGRESS OF REHABILITATION MEDICINE, AND
AMERICAN ACADEMY OF PHYSICAL MEDICINE AND REHABILITATION

BEFORE THE SUB-COMMITTEE ON HEALTH, OF THE COMMITTEE ON WAYS AND MEANS,
U.S. HOUSE OF REPRESENTATIVES

HEARINGS ON PROPOSED NATIONAL HEALTH INSURANCE LEGISLATION

Monday, November 17, 1975

INTRODUCTION

Mr. Chairman:

We appreciate very much this opportunity to appear before your committee and to present our views and suggestions with regard to the directions which the Congress might take in developing a national health insurance program.

I am Dr. Byron Hamilton, Director of Research at the Rehabilitation Institute of Chicago. I am here today to testify on behalf of the American Congress of Rehabilitation Medicine, of which I am a member, and also on behalf of the American Academy of Physical Medicine and Rehabilitation; both have endorsed my statement and authorized me to speak for them.

The American Congress of Rehabilitation Medicine is a multi-disciplinary organization whose members represent all the professions that make up the rehabilitation teams which care for the nation's disabled people. Closely related to the American Congress is the American Academy of Physical Medicine and Rehabilitation, composed of physicians who are Board-Certified members of the speciality of Physical Medicine and Rehabilitation.

Mr. Chairman, as you know the Rehabilitation Institute of Chicago is one of the nation's largest comprehensive medical rehabilitation centers, and it is also one of the newest. It represents a commitment of seven million dollars in federal money and 19 million dollars from private citizens, corporations and

foundations of Chicago and the midwest; a commitment to conserve our human resources, those disabled by injury, disease or defect of birth, through the process of medical rehabilitation.

We will reiterate previous testimony before this committee (April 26, 1974) by indicating that the American Congress of Rehabilitation Medicine and the American Academy of Physical Medicine and Rehabilitation both support a federal law which would require health insurance coverage of a uniform and broad nature for all Americans regardless of income.

The primary purpose of the testimony today, however, is to point out the necessity of including coverage of comprehensive rehabilitation services in a national health insurance program and further, to recommend that there be included a clear and realistic definition of what the rehabilitation services are.

Of particular concern is that appropriate and timely care be provided for "catastrophic illness". These are the illnesses which produce severe disablement for long periods of time with very disruptive consequences to the individual, the family, and to society which may be burdened with a dependent, non-productive member as well as high costs for long-term care and income maintenance. We have come to recognize that the rehabilitation process, applied appropriately and early, results in less long-term disablement, higher levels of life function, less family disruption and importantly, less cost for care and income maintenance in the long run.

We would like to devote the remainder of this testimony to describing the magnitude of the need, what the rehabilitation process is and document the effectiveness of that process in restoring our human resources and the cost savings in doing so. Further, we would like to point out some of the consequences of inadequately defining rehabilitation services in a health insurance plan and, finally, indicate an appropriate definition of rehabilitation services for a national health insurance program.

WHO NEEDS REHABILITATION SERVICES?

Each year in the United States new injury and disease directly affect the lives of millions of people. The disability which results varies in type and extent. The National Safety Council indicates that in 1974, 380,000 people had permanent impairments resulting from accidents.⁽¹⁾ Of the 10,000 children born each year with cerebral palsy, nearly all have disabling impairments;^(2,3) and many of the 617,000 children under age 17 sustaining burns have functional impairment.⁽⁴⁾

The major killing diseases, heart attack, stroke and cancer, result in disability more frequently than death during the first several years after onset. Each year there are 775,000 new heart attacks,⁽⁵⁾ 440,000 new strokes⁽⁶⁾ and 665,000 new cancers detected.⁽⁷⁾ As you know, attempts to treat and cure cancer result frequently in considerable impairment and dysfunction.

Appropriate and timely rehabilitation services can reduce disability, and restore function and ability to work for the majority of these people, including the most severely, catastrophically disabled.

THE REHABILITATION PROCESS

Let us look at the rehabilitation process. Your attention is directed to the appended diagram, entitled, "The Return of Life Functions Following Disability: The Role of Medical Rehabilitation". On this illustration is portrayed the sequence of events which occur over time when an individual sustains serious acute injury or disease.

As you can see on the left, a person functioning normally before disability onset has a high level of life function. This means that he or she has essentially normal physical function, can feed and dress himself, walk and talk, think and act independently, can sustain work and family responsibility and

THE REHABILITATION PROCESS (Continued)

take part in social, recreational and all life's other activities. At the onset of serious acute injury or disease (such as spinal cord injury or stroke), these life functions decrease precipitously. If the insult is very severe all the life functions cease and death ensues. Should the insult be less severe and acute care medicine can effectively deal with the ruptured blood vessels, broken bones or massive infection, death is averted. Such is the case in the illustration. However, the level of life function is very low at this point; all those activities such as walking, talking or functioning independently or working are not possible. From this point what happens depends to a large extent on the availability of comprehensive rehabilitation services which can return function to the highest level, in the shortest time and maintain it there for as long as possible. It is possible to document that if little or no rehabilitation services are provided, the course of recovery tends to follow the dotted curve; that is, a relatively low level of life function returns. With comprehensive rehabilitation services provided early the solid line curve results and the outcome is a higher functional level. We will discuss later some of the recent documentary evidence to support these statements.

Required in this intensive rehabilitation process is a coordinated multi-disciplinary team with the following functions and staff:

Self-Care, including eating, dressing, homemaking and prevention of medical complications, is retaught by nurse, occupational therapist, inhalation therapist (when appropriate).

Mobility, including transfer from bed to chair, wheelchair to automobile, etc., and ambulation with braces or prostheses is retaught by physical therapist, primarily. Orthotist or prosthetist are needed for device fabrication and fitting.

THE REHABILITATION PROCESS (Continued)

Communication, including return of speaking, writing and critical assessment of hearing is carried out by speech therapist and audiologist (when appropriate).

Work/School preparation, including pre-vocational training by occupational therapist and vocational counseling, training and placement by vocational staff, are a critical element in the rehabilitation process, often supported by vocational rehabilitation funds.

Socialization, including re-integration into family and community are carried out by psychologist and social worker. Some teams include a recreation therapist who returns the skills needed to overcome architectural, transportation and social barriers that impede shopping, socialization and recreation in the community.

Medical Management and Coordination are carried out by the team physician.

It should be pointed out that these multi-disciplinary teams may be found in many hospitals and all comprehensive medical rehabilitation centers; such an array of services is not provided by skilled nursing facilities (SNF) or by intermediate care facilities (ICF). SNF or ICF are not comprehensive rehabilitation facilities and they cannot have the impact on severe disability that the comprehensive services have. The timing, extent and intensity of the medical rehabilitation process are unique and overlap little with the role of the SNF or ICF. This distinction should be crystal clear and a national health insurance program inclusive of "catastrophic" care should reflect this understanding.

EFFECTIVENESS OF COMPREHENSIVE MEDICAL REHABILITATION

The outcome effectiveness of comprehensive medical rehabilitation can perhaps best be measured in terms of increase in level of independent function and return to work. "Independent function" means ability to move one's self from place to place and take care of one's own eating and dressing without assistance from another person. "Work" means gainful employment and includes school or homemaking.

Several recent studies, including one requested by Congress⁽⁸⁾, indicate the effectiveness of comprehensive medical rehabilitation on increasing independent function.^(8,9) Importantly, they all find similar results. The level of independent function on admission to rehabilitation is about 35% of normal for stroke, spinal cord injury, arthritis and amputation patients combined. At discharge, function has risen to 70% of normal; and at follow-up, 2-3 years later, it is up to about 75% of normal.^(8,9)

Return to "work" following comprehensive rehabilitation for severely disabling spinal cord injury is approaching 70% of patients.^(10,11)

Lifetime cost savings in terms of decreased nursing and medical care and increased earnings are now approaching \$60,000 per patient following comprehensive rehabilitation for acute spinal cord injury.⁽¹⁰⁾ For the 5,000 Americans with new spinal cord injuries just this year this represents a national lifetime net savings of \$300 million dollars; just for careful rehabilitation of one type of catastrophic injury! Can you imagine what similar cost savings might be for all the major disabling diseases and injuries which occur new each year?

Nothing at all has been said about what independence and ability to work means to an individual who has been severely disabled and to his or her family. The returned opportunity for life, liberty and the pursuit of happiness is priceless.

CONSEQUENCES OF NOT ADEQUATELY DEFINING
REHABILITATION SERVICES COVERAGE

In the past, Medicare and other health insurance plans have not adequately defined or specified rehabilitation services and have not provided for comprehensive services, or for the duration actually needed. As a consequence, there has emerged a problem known as retroactive denial of payment of services. The insurance carrier will not pay for certain rehabilitation services delivered or for the duration required because such services or duration are not stipulated in the plan. In some rehabilitation hospitals this has led to very significant loss of revenue or caused the patient or family significant financial hardship.

For example, a number of Federal District Court decisions in the past year have been necessary to reverse HEW determinations that care in rehabilitation hospitals was not reimbursable under Medicare. HEW decisions in these cases reflected no understanding of what rehabilitation is and HEW determined that the care provided was either custodial or nursing home care. In every case this past year (five), HEW has lost on the issues and the courts have concluded that the care was necessary rehabilitation care. However, these cases make it clear that the law needs a definition of rehabilitation care, at least as it relates to inpatient rehabilitation to prevent such retroactive denials.

The full extent to which retroactive denial is actually preventing needed rehabilitation services is not known. However, the problem can be overcome with an adequate definition of rehabilitation services and realistic duration of services for the needs of the patient.

RECOMMENDATIONS

It is vital that a national health insurance program provide appropriate coverage of medical rehabilitation services for the disabled.

The American Congress of Rehabilitation Medicine, the American Academy of Physical Medicine and Rehabilitation and the Interspecialty Council of the American Medical Association endorse and recommend the following definition of medical rehabilitation services for inclusion in a national health insurance program:

"Rehabilitation Services

"(bb) The term 'rehabilitation services' means a multi-disciplinary approach to services furnished to those with one or more chronic, disabling diseases or injuries under a plan of management directed by a qualified physician related to the achievement of specific outcomes regarding functional capacity or the prevention of deterioration in the disabling condition of the patient; including, where required, any one or more of the following:

" 1) physician services, including diagnostic, evaluation and therapeutic services;

"(2) physical therapy, occupational therapy, inhalation therapy;

"(3) speech pathology and audiology;

"(4) prosthetic and orthotic devices, including testing, fitting or training in the use of prosthetic and orthotic devices;

"(5) social and psychological services;

"(6) nursing care provided by or under the supervision of a professional nurse;

"(7) supplies, appliances, and equipment, including the purchase or rental of equipment; and

"Rehabilitation Services (continued)

"(8) such other services as are medically necessary for the mental and physical restoration of the patient, or the prevention of his deterioration, and are ordinarily furnished as rehabilitative services by a hospital or rehabilitation facility."

It should be re-emphasized that current medicare definitions do not specify coverage of each of these essential services and that unless they are so specified it is unlikely that comprehensive rehabilitation services can be delivered and the expected improvement in life functions achieved, particularly for the catastrophically disabled.

Further, comprehensive rehabilitation services need to be covered as soon after onset of disability as practicable, preferably in conjunction with acute care when that is possible.

Coverage of medical rehabilitation must include in and out patient services to the extent required by the nature of the catastrophic impairment and degree of disability. It is recommended that guidelines of coverage for both type and extent of services be determined by the designated Professional Standards Review Organization (PSRO) through the processes of standards development, utilization review and medical audit.

It will be essential that high standards of care be maintained in the provision of comprehensive rehabilitation services. Minimal requirements for such care include: 1. A Qualified physician managing the care plan, 2. A care plan with clearly defined objectives or goals which are appropriately adhered to.

CONCLUSION

In summary, we support an effective national health insurance program; we strongly recommend that comprehensive medical rehabilitation services be clearly underwritten in such a program; there should be no ambiguity about the intended purpose of the services or the specific type of services required. The testimony here is provided to assist the Committee in defining this essential element in our national health insurance plan.

May I leave you with this thought:

Humpty Dumpty sat on a wall;

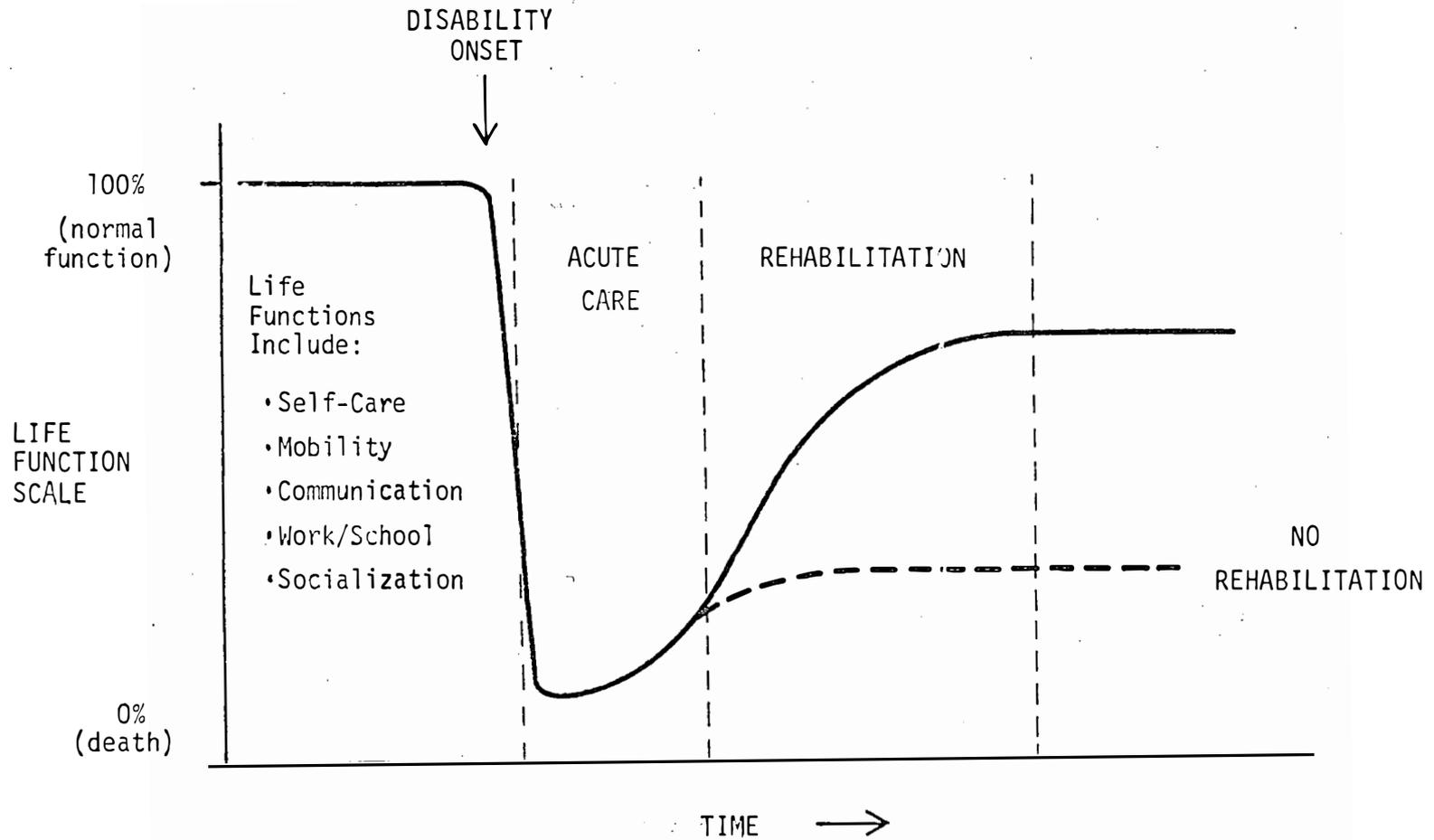
Humpty Dumpty had a great fall.

All the King's horses and all the King's men

Did put Humpty together again!

Mr. Chairman, this concludes our written testimony, and we are available to answer any questions. Thank you for allowing us to appear before this Committee. We are also available at any time to assist the Committee in its analysis of the proposals recommended.

THE RETURN OF LIFE FUNCTIONS FOLLOWING DISABILITY
THE ROLE OF MEDICAL REHABILITATION



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PENNSYLVANIA REHABILITATION ASSOCIATION

July 29, 1976

Governor Jimmy Carter
Plains
Georgia 31780

Dear Governor Carter:

Pennsylvania Rehabilitation Association's membership congratulates you on your selection as the Democratic candidate for the President of the United States.

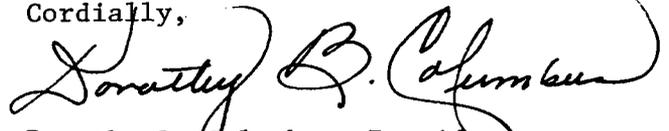
It was heartening to note that during your acceptance speech you did mention the disabled citizens of the United States. Countless candidates in the past have totally neglected this fast-growing citizen group. We are pleased that you have appointed Senator Philip Hart and Esther Peterson to head up your task force on consumer issues, because these two people are very aware of the needs of the disabled. We are certain that they will perform their tasks conscientiously.

Our organization represents over 1,500 members who work in a wide area of rehabilitation programs in the State of Pennsylvania. Enclosed is a copy of our Summer Newsletter. We would very much like to have a statement of intent regarding the Carter plans for the disabled in a future newsletter. If we receive this information from you or your staff by August 15, we will be able to include it in our next PRA News scheduled for September publication.

If additional information is needed concerning the Pennsylvania Rehabilitation Association, or if you have any questions, please don't hesitate to contact me at 596-1295 (business) or VI 8-2774 (home) or our Secretary, Elizabeth J. Hamilton at 854-4376 (business) or 667-0546 (home).

Our very best wishes to you for a successful campaign.

Cordially,



Dorothy B. Columbus, President
3120 W. School House Lane
Franklin Building, B-6
Philadelphia, PA 19144

DBC:pw
Encl.

Memo

From

BILL JOHNSTON

To: BOB HAVELY

FROM: BILL JOHNSTON

DIANNE ROUPE

↳ Exec. Director

National Rehabilitation
Association

1522 K ST Wash D.C.

202 659 2430

~~Hampden~~ ^{Mr.} Harrington

Hogan & Hartis

202 331 4646

Need to speak at National
Convention

File



Sylvia Porter

REHABILITATION: V

There is no politics as such in the horrifying fact that more than 22 million handicapped persons are pleading for—but not getting—rehabilitation so they can become productive contributors to our economy rather than a destructive burden on all of us. No poll ever has been taken to determine whether the 12 million Americans in the 16-64 age group who are severely handicapped—one in every 11 adults! — are Republicans or Democrats. No one can pin the label of a political party on the statistic that 440,000 new cases of stroke are detected in the U. S. every year.

But there is plenty of hard economics in the above non-political facts. For documentation has been piled on documentation to prove that every \$1000 invested in rehabilitation of our disabled returns \$9000 to our economy. The total increase in the lifetime earnings of rehabilitated persons ranges from 6 to 20 times each dollar spent for their rehabilitation.

* * *

After rehabilitation more than 80 per cent of spinal injury patients are able to do some type of gainful work, and with proper care, their life expectancy is within two years of normal. If these years were spent in a nursing home, costs could well top \$500,000 per case. A terrible waste of dollars, a worse waste in terms of human beings.

And there also is plenty of hard business judgment in programs of U.S. corporations to employ the handicapped because they surpass by whopping percentages the records of the average

worker on safety, job performance, loyalty, absenteeism, etc.

It is against this non-political, pro-business background that the Nixon and Ford Administrations now stand condemned in the vast spheres of rehabilitation medicine, charitable organizations focusing on rehabilitation and forward-looking business enterprises. Among the failures of which they are accused:

—Either trying to sabotage rehabilitation programs for our millions of handicapped by non-support of basic legislation or by non-compliance with laws on our statute books. As Rep. John Brademas (D-Ind.), chairman of the House subcommittee on select education, said as far back as 1973:

"When word gets out across the country of what I perceive to be a clear intent on the part of the Administration to undermine and weaken and, if possible, to dissolve the federal-state vocational rehabilitation program, there will be, I think, very widespread opposition... the most militant opposition."

—Deliberately trying to downgrade the rehabilitation programs through appointments of either uninformed or woefully inferior administrators to key positions and by pursuing policies so aimless as to all but kill the Rehabilitation Services Administration.

Despite a substantial broadening of RSA's responsibilities in recent years, the staff resources in RSA are considerably less than in 1967—almost 10 years ago. The head of the RSA, Dr. An-

drew S. Adams, is widely criticized for his lack of experience and weak leadership. (The RSA programs survive primarily because they're largely state-run and have the strength of a 54-year history behind them.)

—Footdragging in every area. For instance, the 1973 Rehabilitation Act mandated the President to call a White House Conference on Handicapped Individuals to stimulate a national assessment of problems and solutions.

Ford belatedly announced the conference on Nov. 22, 1975, set the date for this December. It won't be held, though. It has been delayed again. Now the date is May 1977.

Research is being neglected. Sheer inertia is burying essential programs. Priorities are being shifted constantly, and depend more on whim than scientific merit.

* * *

What can you do, a mere individual?
Let your Congressman know you realize the meaning of the defaults. Tell the White House in unmistakable terms that you want the handicapped to have all the opportunities of first-class citizenship in education, jobs and travel. Demand that our laws be administered by effective leaders.

"Ours was once the greatest rehabilitation program in the world," says Dr. Edward W. Lowman, professor of rehabilitation medicine at NYU Medical Center. "We must make it so again."

"The waste in economic terms is as incredible as in human and social terms," insists Dr. Howard A. Rusk, pioneering chief of the Institute of Rehabilitation Medicine here. "When the public realizes it, there will be cries of anguish and demands for change."

— Last of Five Columns.

RECEIVED OCT 7 1976

President Ford Committee

1328 L STREET, N.W., SUITE 250, WASHINGTON, D.C. 20036 (202) 457-6400

October 1, 1976

Cleo B. Dolan
Executive Director
The Cleveland Society
for the Blind
1909 East 101st Street
Cleveland, Ohio 44106

Dear Mr. Dolan:

Thank you for your recent letter, and for the congratulations you offered. Needless to say that when I last visited with you, I did not know what surprises the future held.

As Republican Vice Presidential nominee, I appreciate the opportunity I have to draw attention to problems faced by the disabled, and to emphasize the tremendous potential these persons possess. Through our united efforts, I am confident that progress for the handicapped will be achieved.

As before, I thank you for sharing with me your views of Dr. Andy Adams. Although we may not agree on our evaluation of the man, I hope you will continue to share with me your thoughts on the topic.

Also, was glad to see your enclosed information, and noticed in particular your rather partisan attitudes in the solicitation of campaign contributions. This seems to be a rather narrow approach to use when choosing the next President of the United States.

Sincerely yours,



BOB DOLE

BD:mww

Bill

Johnston

AMERICAN COUNCIL OF THE BLIND

Suite 506 • 1211 Connecticut Avenue, N.W. • Washington, D.C. 20036 • Telephone: (202) 833-1251

REESE H. ROBRAHN
DIRECTOR OF RESEARCH
AND GOVERNMENTAL AFFAIRS

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Knoxville, Tennessee 37920

EX-OFFICIO
Mary T. Ballard, Editor
The Braille Forum
190 Lattimore Road
Rochester, New York 14620

October 19, 1976

Jimmy Carter
Plains, Georgia 30301

Dear Mr. Carter:

I enclose a copy of an article written by Sylvia Porter which was published in many newspapers throughout the country: "Rehabilitation: V".

Our experience and knowledge concur substantially and forcefully with the conclusions and criticisms stated in this article. We have read your statement, "Jimmy Carter on Americans with Disabilities", and we would like to be assured of your policy and intention about ineffective and reactionary personnel in HEW and particularly in the Rehabilitation Services Administration. We can and will at an appropriate time furnish detailed documentation of such defaults and ineffectiveness.

I enclose a copy of a letter which indicates the kind of entrenched support which exists for the continuation of these deplorable conditions.

Sincerely,

AMERICAN COUNCIL OF THE BLIND

Floyd T. Qualls /lfh

Floyd T. Qualls
President

FTQ:lfh

cc: Reese H. Robrahn
American Council of the Blind
1211 Connecticut Avenue, NW Suite 506
Washington, DC 20036

Enclosure

Dear Mr. Qualls:

Gov. Carter has forwarded your letter of October 19 to me. I can assure you of the Governor's intense commitment to providing effective, efficient, and sensitive government services to all those who ~~need~~ who need them.

Ⓟ Thank you for your letter. If I can be of further assistance, please call on me.
Sincerely, Robert S. Havel, Health Issues Coordinator, National Issues & Policy

JIMMY
CARTER

WALTER
MONDALE



Leaders, for a change.

Handwritten: *Handely*

October 15, 1976

To Glenn Wilson

I really appreciate your outline regarding a nationwide system of health distribution. It is excellent, and will be of great help to us.

With best regards.

Sincerely,

Jimmy Carter

JC:scs





THE UNIVERSITY OF NORTH CAROLINA
AT
CHAPEL HILL

Office of the Dean
The School of Medicine

The University of North Carolina at Chapel Hill
126 MacNider Building, 202 H
Chapel Hill, N.C. 27514

October 8, 1976

October 15, 1976

Governor Jimmy Carter
P. O. Box 1976
Atlanta, Georgia 30301

Dear Governor Carter:

Dean Fordham has shared your exchange of correspondence with me and has asked that I outline for you some of my thoughts with respect to a nationwide system of health distribution of great help to us.

There appears to be, across the political spectrum, much agreement that health care is the right of every citizen. There are several proposals now before the Congress to achieve this objective. These legislative proposals vary widely and represent deep philosophical differences on the best approach to providing health care to the American people.

We are persuaded that if the American people are to have quality health care at a socially acceptable cost, a national health policy should be developed before the enactment of national health insurance. This policy should: (1) specify the objectives, (2) establish a national goal on the aggregate supply of health personnel, especially physicians, (3) develop and extend present approaches to the problem of geographical and specialty maldistribution of physicians, (4) establish criteria for hospital beds and their appropriate use, (5) establish a financing mechanism with cost containment as an inherent part of the financing, and (6) design appropriate allocations from total resources with respect to direct services, education and training, and research.

Public dissatisfaction and uncontrolled costs in the health area are in substantial measure related to the failure to develop a coherent national policy. State and federal governments stimulate the development of more personnel on the assumption that more personnel will thus be better distributed geographically and make services more accessible. These

Governor Carter

2. October 8, 1976

W. W. ROLINA

approaches neglect the major impact that organization and financing have upon access to care. Furthermore, these uncoordinated manpower developments have failed to take into account the short and long-term cost implications of major increases in health personnel. As we seek to solve the manpower problems, in terms of numbers and distribution on the one hand, and organization and financing problems on the other, it will be critical that these efforts be coordinated. Approximately half of the additional costs for health care over the past several years have related to inflation, not additional service. A more equitable financing of medical care services could create major problems in providing the services unless coordinated with appropriate manpower and organizational approaches.

The increased number of physicians and other health professionals in the educational pipeline now and over the next few years represents a remarkably expanding base of health professional manpower. While it is not reasonable to expect that numbers alone will provide an appropriate redistribution, the numbers appear to be such that some favorable redistribution may occur.

It seems likely to us that substantial changes must be made in the financing and organization of health services if full advantage of the improving manpower situation is to be taken in terms of increased access to quality medical and health care services for all of our citizens. A key problem concerns what substantial changes can be made which will be consistent with the democratic principles of our country and, which at the same time, will offer solid prospects for improvement of distribution without alienating the health professions. This has been a most troublesome issue and no proposed solution to date has shown high promise for bridging these concerns. Perhaps the increasing development of prepaid health plans and the increasing tendency of physicians and other health professional workers to be part of organizations providing health care can be taken as a key starting point for making positive proposals. For example, suppose the federal government should determine to provide capitation support for medical and health care services for all of its citizens, including incentives for prevention and early ambulatory treatment (as opposed to hospitalization), and incentives for avoiding duplication of services and facilities? Would it be possible, working with the professions and with the insurance industry, to develop a capitation plan which would assure access to quality care for all citizens, support the health professions and provide incentives for prevention and ambulatory care? It would seem to us to be essential to develop such a plan in full collaboration with the practicing professions as well as with the consuming public and their legislative representatives.

personnel will thus be better
facilities more accessible. These

We believe that there are several key approaches to an improved distribution of health and medical services in the United States. The first set of issues has to do with the distribution of health professional manpower to provide the services. As described in Dr. Fordham's earlier letter to you, the North Carolina Area Health Education Center's Program is one which regionalizes health education through any entity, in this case the State of North Carolina, so that educational efforts in collaboration with the University provide that multi-county regional health manpower needs are met.

There are aspects of distribution of health professional manpower which the educational programs cannot satisfactorily address and which need attention. These include, for example, reimbursement. At present, it is a financial disincentive for physicians and other health professionals to locate in underserved areas, not only because of relatively less affluent clientele but because of reimbursement policies over which the Federal Government has control. We need to re-examine and modify the reimbursement policies to eliminate the financial disincentive for service in underserved areas. The National Health Service Corps is another approach. The full potential of the National Health Service Corps approach, by which part or all of the student's education is subsidized in return for a period of service in an underserved area, is not predictable at this time. The program is relatively young. Similar state programs have not been remarkably successful over the years. There has been a tendency for some students to pay out in cash and for those who carry out their service to leave that site of practice when the period of required service is completed. This latter course does not lend stability of health professional manpower to a community, although it may be helpful for a given period of time. Nevertheless, we believe that the National Health Service Corps approach, if kept voluntary, has merit and will contribute positively to the solution of a better distribution of health professional manpower.

We must make every effort to avoid the adversarial relationship between the providers and consumers which has developed in the United Kingdom and which is part of a bureaucratic morass which exists there now. Can a civilized people tackle this problem together? A dictatorial plan, superimposed upon the professions from the federal level, could result in such an adversarial relationship and could undermine progress now being made toward the solution of some of these problems. But we are inclined to believe that with strong leadership of a new president sensitive to the needs of the underserved communities, the general public and the providers, a common effort could be mounted to assure better access for all of our citizens to medical and health care services, reduce many of our wasteful costs and provide equitable remuneration to providers.

There are other important ways in which the work of the providers might be improved, through better organization of services, through reduced paper-work, through reduced bureaucratic requirements and through enhanced services, educational opportunities. Costs for these matters could be substantially offset by some of the incentives provided in the prepaid approach.

I recognize that we have given you but a bare outline of how we construe the major issues and possible approaches in this vital field. I hope that these views will be helpful.

With all best wishes,

Yours truly,
Glenn Wilson

GW:lj

...service Corps is another approach. ...Community Health Services service in an ...AHEC Program Director is relatively young. ...successful over the year. There ...cash and for those who pay out ...period of required service is ...stability of health professional manpower ...given period of time. Nevertheless, ...kept voluntary, has ...of health ...relationship between the providers ...part of ...people tackle this problem ...from the federal level ...programs now ...incited to ...effort ...and provide equitable remuneration

**JIMMY
CARTER
WALTER
MONDALE**



Leaders, for a change.

October 15, 1976

To Don Herzberg

I appreciate your update regarding the work of the HPC Advisory Board.

Although the Board will no longer exist as an official entity, I sincerely hope the former Board will continue to lend their wisdom and insight to the Center.

I appreciate your support, and will do my best not to disappoint you.

Sincerely,

Jimmy Carter

JC:scs



GEORGETOWN UNIVERSITY
WASHINGTON, D.C. 20057
GRADUATE SCHOOL

OFFICE OF THE DEAN

October 8, 1976

The Honorable Jimmy Carter
Plains
Georgia 31780

Dear Governor Carter:

I am writing to bring you up to date on the results of the third annual Advisory Board meeting of the Georgetown University Health Policy Center. We realized that you couldn't possibly have attended the meeting, given your campaign schedule, but hope to maintain your continued involvement, if only through letters and publications. (One of the most recent publications, Paper Victories and Hard Realities, is enclosed.)

At the September 17th meeting in Washington, there was much discussion concerning the appropriate role for the HPC Advisory Board. The outcome has been a decision to discontinue the Board in its formal capacity, but retain former Board members, if they are willing, to serve as informal advisors to or "friends" of the Center.

I hope we can count on your continued support. I believe the Health Policy Center is making a valuable contribution to the understanding of state concerns in health policymaking, and hope you will feel free to call upon us for assistance in the future. In the meantime, let me express my deep appreciation for the time you have given the Center in the past, and wish you success in the coming election.

Sincerely,



Donald G. Herzberg
Dean

Enclosure

CARTER
WALLEN
MONDALE



Leaders, for a change.

Henry

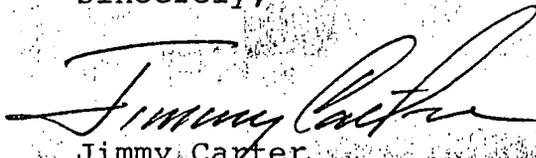
October 21, 1976

To Alan Toppel

Thanks for your kind words about my remarks
to the National Rehabilitation Association.

I am grateful for your support and that of
the Commission, and will do my best to deserve
your confidence.

Sincerely,



Jimmy Carter

JC:scs



COMMISSION ON ACCREDITATION OF REHABILITATION FACILITIES

carf

4001 WEST DEVON AVE • CHICAGO, ILLINOIS 60646 • 312-282-8787

ALAN H. TOPPEL, Executive Director

SPONSORING ORGANIZATIONS

American Hospital Association Section on Rehabilitation and Chronic Disease Hospitals

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National Association of Hearing and Speech Action

National Easter Seal Society for Crippled Children and Adults

National Rehabilitation Association

October 11, 1976

Mr. Jimmy Carter
Plains, Georgia 31780

Dear Mr. Carter:

I have just recently received your prepared statement to the National Rehabilitation Association, dated September 19, and found your thinking so sensitive and relevant that I wished to so respond to you.

Please know that you have our wholehearted support and complete endorsement in your commitment to the task of promoting quality rehabilitation for all handicapped persons who seek the fullest measure of life. The leadership role which you have taken in the past is a testament to your ability to fully grasp the problem, and a demonstration of your skill and competence to realize solutions. I can only hope you are provided with the opportunity to aggressively address yourself to these challenges which can prove to be programmatically sound for the people, and an economically prudent investment for the country.

Since the Commission on Accreditation of Rehabilitation Facilities was formed, ten years ago, we have emerged as the quality-control intermediary for all of the variety of rehabilitation programs. Our goal of upgrading the level of performance of facilities, and the resultant effects on people served has been acknowledged in the public and private sectors, by policymakers, purchasers, providers, and consumers of rehabilitation services. In addition, we have been recognized for our creative leadership role in responding to the accountability issue by focusing on the results achieved in facilities through program evaluation systems.

I am taking the liberty of enclosing our recent Report. I believe you will find our Bicentennial Message both of particular interest to you, and one which captures the basic philosophy of your entire campaign.

Sincerely,

Alan H. Toppel
Executive Director

AHT/kd

Enclosure

Presidential Campaign Committee, Inc.

WALTER
MONDALE



Leaders, for a change.

Harrelly

October 22, 1976

To Cynthia Good

I appreciate your concern for Americans
with disabilities.

I hope that I may win your confidence as
well as your support before the election.

Sincerely,

Jimmy Carter

JC/js

465 West 23rd St., #3-K
New York, NY 10011

October 5, 1976

Mr. Julius Shaw
New York Citizens Committee for Jimmy Carter
Disabled Community for Jimmy Carter
730 Fifth Avenue
New York, NY 10019

Dear Julie:

At your suggestion I carefully read Governor Carter's four page statement "Jimmy Carter on Americans with Disabilities." While it was not as explicit as I had hoped, he did admit to some broad promises to a policy for the disabled, as you indicated.

Under the circumstances, I feel that this statement alone is not a promise on which disabled people may rely. Notwithstanding, I personally believe he is committed to his ideals of equal opportunity and humanism.

However, as a person in public administration by education and career, any beginning involvement in the campaign at this point is contraindicated with the concept of rational planning and cost-effectiveness. My efforts are still more beneficially directed toward my ACCD, CPD, and DIA commitments.

Sincerely,

Cynthia L. Good

cc: Ms. E. Fiorito
Mr. W. vanden Heuvel
Mr. B. Bull
✓ Gov. J. Carter
Mr. L. Allison
Mr. J. Davis

*See previous correspondence to L. Allison and J. Davis (Sept. 8, 1976).

Jimmy Carter Presidential Campaign Committee, Inc.

Greater Los Angeles Council on Deafness, Inc.

621 SOUTH VIRGIL AVENUE, LOS ANGELES, CALIFORNIA 90005

TELEPHONE Voice and TTY (213) 383-2220

FROM SAN FERNANDO VALLEY: 780-2200

FROM SAN GABRIEL VALLEY: 579-4474

A non-profit agency dedicated to the social, economic, educational and cultural welfare of the hearing impaired through member organizations.

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of the Deaf
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Hearing Impaired Parent Group

October 12, 1976

Governor Jimmy Carter
c/o Robert S. Havely
Health Issues Coordinator
National Issues and Policies
P.O.B. 1976
Atlanta, Georgia 30301

Dear Governor Carter:

I was happy to receive your long overdue letter because many people here are telling me that the Republican Candidate for Vice President, Dole, is the real friend of the deaf and the handicapped. Being a registered Democrat myself, I must admit that this bothered me. However, I am assured by your position paper on Americans with Disabilities, that you do have the interests of the handicapped at heart and in your mind. I am hopeful that you will not forget them if you are elected on November 2.

I am a deaf teacher of the deaf and hard-of-hearing in a day school program and have two Master Degrees, one in Special Education and Rehabilitation and one in Administration. I am certain that I can be of assistance to you regarding your Advisory Committee for Disabled Americans as I have had many years of experience. I am waiting word from Ms. Janet Oliver regarding this.

I represent the deaf people in the Greater Los Angeles area as the President of this organization, AKA/GLAD, and I am the 1st Vice-President of the California Association of the Deaf. Our influence is felt throughout the state and the country. We are the activists of the deaf community and with good reason.

I was glad to read in your position paper on disabilities that you have made a commitment to the proposition that disabled people deserve to control and shape their own lives. For too long we have been "managed" by hearing people who make decisions for us regarding our mode of communication, the kind of education we should have, the jobs we are able to handle, and other matters affecting our adult lives. It is extremely

important, therefore, that you and your advisory committee stress this principle of self-determination for all handicapped people. Lack of self-determination is the basic reason why we deaf have not been accorded civil liberties in social living, in education, in employment and in communication (television, telephone, etc).

Too often responses to our needs have been "tokenism" and are only beneficial to the elite of the deaf community. The vast majority of the deaf are ignored and/or by-passed because of the difficulty of serving them due to their unique communication problem. The deaf have this communication problem through no fault of their own. The fault should be put where it belongs, with the parents and schools, who put too much emphasis on making deaf people into "hearing people", instead of making them emotionally happy deaf people.

We, too, are overwhelmed by bureaucracy in our nation's capitol. The "deaf bureaucracy" in Washington, D.C. is a good example. These people are supposed to represent all the deaf, but due to their proximity to the President's Commission on the Handicapped, the eastern part of the country is endowed with many services for the deaf, while the rest of the nation suffers.

These people in the bureaucracy just mentioned have not been successful in promoting total-communication from age zero to adulthood in schools or in breaking through the accessibility barriers of various public and private agencies to provide equal social services to the deaf. Absolutely nothing has been done to persuade the telephone companies to provide tele-typewriter=phone modems at a low cost, with services comparable to what you might expect of telephone companies. Although such equipment is presently in use, it is too expensive for the average deaf person to purchase. Such things must be done by the phone company as part of their public service, which should include ALL people.

Although much of the country enjoys captioned and sign language news programs, we in Los Angeles have very little of this service. There is a comparatively inexpensive decoder that would permit 14,000,000 hearing-impaired people in our nation to enjoy captioned television programs without distracting others who may not desire captions. The Federal Communication Commission could serve us through the use of Line 21, but commercial interests want the television people to make Line 21 available for advertising purposes. This injustice is outrageous!

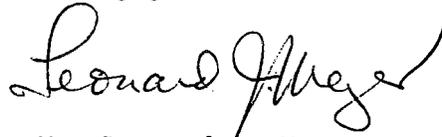
By now you must realize the difficulties we are encountering because of our communication lack. Therefore, we are enclosing several articles which graphically describe our problems. One is an article by F.A. Caligiuri, a deaf man, and chairman of our communication and advocacy committee.

I wish to conclude my letter with an emphasis that the deaf all over the country be contacted for their views on their problems ... not just the professionals, but the deaf consumers as well. This is important, as we are tired of the top dogs who are governing the lives of the deaf people ... they are only interested in maintaining their status quo. The invisible handicap of deafness, which Helen Keller once said was worse than blindness, can be reversed, and the deaf can become a valuable asset to our country. The fertile minds of the deaf, if permitted to be nurtured from infancy, through Total Communication, can be a thing to behold. This has been proven by many research projects and this form of communication should become mandatory in all schools for the deaf.

I hope this letter has enlightened you on many of the problems we face and which we can overcome, given the right opportunity.

Please feel free to consult me at any time. I am at your service.

GLADly yours,

A handwritten signature in cursive script that reads "Leonard J. Meyer". The signature is written in dark ink and is positioned above the typed name.

Mr. Leonard J. Meyer
President

LJM:hm

September 25, 1976

Mr. Max N. LaVine
1812 Epworth Drive, N.E.
Huntsville, Alabama 35811

Dear Mr. LaVine:

Thank you for your letter of July 7. I apologize for taking so long to reply. Governor Carter has referred it to me as I will be handling health care issues on the staff level during the campaign.

We appreciate your concern about the changes proposed in upcoming tax legislation. I want to thank you for the information you sent along concerning the effect of the tax bill on disabled Civil Service employees.

Any further ideas or information you might wish to send would be most helpful. Again, thank you for your interest and support.

Sincerely,

Robert S. Havelly
Health Issues Coordinator
National Issues and Policy

RH:j

July 7, 1976

Honorable James Carter
Plains, Georgia

Dear Governor Carter:

Reference House Ways and Means Committee's submitted version of its new tax bill as it regards the permanently and temporarily disabled civil service workers who are retired. To adjust, change, or otherwise cancel the sick pay exclusion would, in my opinion, be grossly discriminatory.

As a former civil service employee I am very disturbed that a body of our elected and qualified officials can be so specific in ways to reduce the benefits of a small salaried disabled group and at the same time can be so vague (and many written articles would make them seem totally unable to even be general) in finding ways to specifically "plug" the tax loopholes enjoyed by higher salaried able-bodied, employed taxpayers and corporations.

Sir, these competent committee members surely realize that in selecting this low salaried group of disabled civil service retired employees they have singled out a group that cannot afford to hire a battery of legal advisors or lobbyists to champion their cause. It, therefore, becomes a "sure" thing to cancel with the least resistance or recourse unless you and your colleagues disapprove.

Some interesting points that the proposed changes in sick pay exclusions to the disabled could bring out: (1) Civil Service Commission management policies many times pressured, recommended, or otherwise caused many employees to retire because they had become totally or temporarily disabled and unable to perform their jobs, and this action may have been correct had not the sick pay exclusion been one of the more important benefits outlined in the management approach. Now subject committee is recommending that the policies be changed, and in many cases the employee under their new recommendations would not be considered disabled but would be considered able to perform a less demanding job. Maybe this policy properly published for utilization in the future would have some merit but to foist this on those employees already retired would be breaking a trust of sorts and could be discriminatory. Many would have chosen a lesser paying position in lieu of

retirement without the benefit of sick pay tax exclusions. (2) The committee recommends that the disabled retirees who receive a \$15,000 plus annuity be penalized on a dollar for dollar basis. That is, for every dollar over \$15,000 received in the retirement annuity the disabled employee would lose a dollar in his sick pay exclusion. This, then, in essence becomes an implied ceiling for disabled CS retirees since the end result is the same. I don't believe I have ever heard of such arbitrary and bigoted judgment. This surely qualifies for a bicentennial revision of the Spirit of '76 phrase and cause--"Taxation without representation". (In this case it should be "Taxation without consideration.") Surely, more thought should be given to the possible precedents this will inevitably open up. For example: If subject committee can justify (and apparently have, at least to themselves) that the maximum retirement annuity that a disabled civil service employee should receive is \$15,000 and after that he will be subject to drastic dollar for dollar denials on exclusions (deductions) then surely they should also carry this over and make it applicable to able-bodied taxpayers. Then the \$15,000 base line can be the maximum for everyone and all "tax loophole deductions (exclusions)" will be reduced on a dollar for dollar basis, thus putting able-bodied taxpayers on a par with the seemingly "singled out" disabled civil service annuitants.

I realize there are many technical and legal explanations and dodges to explain the above away, but I also realize that it is merely so much rationalization. The basic example above will hold true on a moral and democratic basis and a whole library of tax cover-up excuses and reasons would not change the grass root moral intent. If the committee gets their seemingly bigoted recommendations approved, the elected representatives in Washington, D. C. will have established an arbitrary annuity ceiling for disabled civil service employees. I know this is not your intent, but the results will be the same; so why hide it under a denial of sick pay exclusion? This certainly cannot be tolerated as fair treatment.

Attached are some other data that make a disabled taxpayer's morale drop out of sight. With medical and medicine costs rising, etc, it would appear to be more considerate to increase the sick pay exclusion in lieu of reducing same.

Note the data spread attached. Also, with such loopholes, tax exempt bonds and other tax sheltered income that the high income bracket persons and corporations, etc. can and do use to their advantage, it would seem that the subject committee would not have the courage to be able to point the finger at (of all groups) a disabled civil service retired group, saying in essence - here's a place that can be cut and they cannot fight back.

It is evident in many articles that if a tax increase is necessary, many fields are more lucrative than sick pay exclusions for disabled retirees. While this bill was passed by the House and forwarded to the Senate, it is understood the Senate did not act on this bill when the 75 bill was extended for 6 months. Much concern remains, however, that when the extension expires, this bill as passed by the House, may be revived and acted upon by the Senate without revision. I realize this is probably not the only letter you have received expressing concern over the elimination of this sick pay exclusion for CS disabled employees but felt it imperative that I also express my feelings. I implore you to speak out strongly against this unfair and discriminatory recommendation.

Trusting that you will do so, I remain a hopeful taxpayer.

Sincerely yours,

Max W. Javine

1812 E. Swarth St NE

Huntsville Ala

35811

NOTE # 1

Sick pay exclusion proposal in tax bill regarding totally disabled Civil Service retirees. The bill as passed by the Committee is not only discriminatory between able-bodied employees and disabled retired employees but discriminatory within disabled employees as noted by following example:

EXAMPLE: Assume two totally disabled CS employees. One a top management or executive who receives an annuity of \$19,000. Call him employee "B". The other call him employee "A", who was one of the lower salaried employees who worked for employee "B", and he also became totally disabled and retired with an annuity of \$14,900. Below is depicted the general data under both the present regulations and the proposed regulations. This is an example - not a CPA audit.

PRESENT:

<u>EMPLOYEE</u>	<u>BASIC ANNUITY</u>	<u>SICK PAY EXCLUSION</u>	<u>TAXABLE INCOME</u>
"B"	19,000.00	5,200.00	13,800.00
"A"	<u>14,900.00</u>	<u>5,200.00</u>	<u>9,700.00</u>
Difference	4,100.00	-0-	4,100.00

PROPOSED:

"B"	19,000.00	1,200.00	17,800.00
"A"	<u>14,900.00</u>	<u>5,200.00</u>	<u>9,700.00</u>
Difference	4,100.00	4,000.00	8,100.00

Comparisons of results of proposed versus present regulations:

1. Basic annuities remain same for "A" and "B".
2. Sick pay exclusion - Employee "A" receives full exclusion under both plans - Employee "B" sick pay exclusion is reduced dollar for dollar for everything over \$15,000 or a reduction of \$4,000.
3. Taxable income for employee "A" remains the same for both plans Employee "B" taxable income difference with employee "A" increases from a \$4,100.00 difference in present plan to a whopping \$8,100 .00 under proposed tax plan.

Some of the facts in this portrayal and CS are:

1. Both "A" and "B" were Civil Service (CS) employees.
2. Both "A" and "B" are totally disabled CS employees.
3. Civil Service regulations are equitable and also applicable to all, guaranteeing equal consideration and rights to all employees regardless of race, creed, color or physical condition.
4. These CS regulations are the guidelines by which the employees plan their working and retirement future.
5. These CS regulations allow an employee to rise to the level of his potential.

Sir, the above example, which to the best of my ability, depicts generally the truth in how the proposed tax will affect the totally disabled CS retiree.

How would you react if you were employee "B" who had applied your potential and had risen to a salary level whereby your retired annuity was as shown in above example and your employee who was also stricken and also received total disability? Of course, you would feel grateful that the CS retirement plan is (or was) a good one. Since you are qualified for total disability you both receive sick pay exclusion to offset some of the continuing medical costs and this too is very helpful. Then----- along comes a tax committee and with a stroke of a pen a thoughtless and seemingly socialistic approach is passed and the resulting end product is, in essence - "The maximum any totally disabled civil servant deserves is \$15,000 annuity regardless of how many years he worked and regardless of the working salary he achieved and regardless of how his annuity was computed by the Civil Service regulations and regardless of any rights he had under these and other regulations. We the committee know what is best for the masses." Sir, this is certainly a bigoted and a dictatorial decision. Are we truly that far down the road to Socialism?

If you will research this plan that has been rubber stamped by the House, you will see that the above is generally in line. Employee "A" with a basic annuity of \$14,900 ends up approximately with the same as employee "B" whose basic annuity is \$19,000 due to the penalty imposed under the sick pay exclusion approach. Where has the fairness gone? What will happen to initiative and motivation if regulations can equalize everybody in the end? Sure, it can all be rationalized all away by technical phrases and references but the final result will remain. Hastily approved bills stay on and on doing damage that can never be repaired. Will this be another one?

As you can see in this enclosure that the bill, in my opinion, is not only discriminatory between the able bodied and totally disabled (a contest that should never be considered), it is also inconsistent and unfair within the totally disabled category of retired employees. How such an inconsistent, inconsiderate, and very definitely ill-thought-out bill ever got through the House, let alone out of the committee, is very discouraging. Confidence in our elected lawmakers is a must if we

are to survive. Hopefully, you can bring notice to the apparent points of departure from realism.

Surely, allowing the present sick pay exclusion laws as written protecting the totally disabled CS retirees will not bankrupt the country. Why, "plugging" just one of the many "tax loop holes" now allowed in the \$50,000 and over bracket would more than net the tax dollars represented by this portion of the bill.

Hopefully, you can bring out points that will cause the bill to be rewritten.

NOTE 2

REGARDING: Change in Sick Pay exclusion in the House version of the tax bill now before the Senate.

This bill eliminates and/or abrogates the agreement between the Civil Service (Government) and the employees after the fact and should not apply retroactively if it is approved by the Senate. That is, all CS totally disabled retirees who were retired prior to final approval of the proposed bill should be exempt. If passed, it should apply only to subsequent retirement actions. Reason for this:

1. Until this portion of the tax bill was finalized to its present status, the benefits it offered to the disabled employee was the major inducement that management and concerned personnel offices used in encouraging (and pressuring) disabled employees to retire.

2. Many employees not of retirement age who were disabled (and used much sick leave) would not have retired without the sick pay exclusion tax break. This, plus the fact that Civilian Personnel Offices were authorized (rightfully) and did use the tax break point to strongly advise early disability retirement does in essence constitute a contract condition with the employee. To eliminate and/or cancel this condition with the disabled employee who did believe and in good faith did plan his future and retired believing the stated benefits would be forthcoming until age 70 (mandatory retirement age) would certainly be acting in bad faith. Therefore, if the bill is to be approved (it is still a bad piece of legislation in my opinion) it should only be applicable in retirement actions subsequent to the date of approval and signature. To do otherwise will be knowingly placing many disabled retirees in untenable financial conditions because they were faithful enough to believe the Civil Service Regulations.

Belief in management, (Civil Service, Gov't, or otherwise) motivation, career dedication, etc., can only exist under fair treatment and management adherence to the guarantees contained and/or spelled out in the existing governing policies and regulations. Adverse retroactive changes can only result in poor morale and total lack of faith in the management (CSC, gov't) policies. Can we afford much more breakdown in the taxpayers faith in his government and exist as a democracy?

NOTE 3

REGARDING: The elimination of sick pay exclusion for totally disabled CS employees in the new tax bill.

By now, you have noted that I am not in favor of the so-called proud and glaring, as well as discriminating, portion of the bill.

When I read, hear, and see in life and on TV the following which are only a drop in the old bucket, I am much confused in above deliberate attempt to cancel such a minor thing as sick pay tax exclusion for the CS disabled retiree.

a. Untold billions for relief. Yes, much relief is necessary, but the media in all manner of communication have identified such a proliferation of abuse that it seems like pouring good after bad.

b. Rehabilitation of thieves, murderers, rapists, dope addicts, drunks, etc. who, statistics show, when released, the majority end up back in prison again and again - yet, hundreds of millions every year to cure something incurable. At least, that is now the common knowledge that our leaders are publishing.

c. Hundreds of millions and possibly many billions under the heading of relief for mothers with children who have no fathers. This goes on year in and year out. The more children, the more relief. What is ever done to cancel or control, etc.? We taxpayers are not stupid, but sure are tired of paying for such generosity to people who won't work, won't pay taxes, or even contribute just a little self-discipline for the sake of our nation.

d. A railroad fails to make a profit - subsidize by the government is the answer. Only a few hundred million.

e. An airline or an airplane manufacturer does not show a large enough profit - subsidize by the government is the answer. Only a few hundred million.

f. Contract overruns - Add billions and continue hopefully.

g. Cost-of-living increases for Congressmen.

You probably say - what can I do. I don't rightfully know, except "YOU" are in a position to be heard when you speak. I can only vote and do vote,

hopefully, for those who I think will try to control the hundreds of millions and billions that are spent as noted above.

I do ask sincerely, "Where are the financial wizards who serve on committees and can, and do, single out how to change and adjust laws, etc., in order to squeeze out a few more tax dollars from such a minority group as the Civil Service totally disabled retirees, and still can't plug loopholes for high salaried, able-bodied tax sources?"

This bill seems more like a blow at Civil Service than an attempt to raise any meaningful amount of dollars. Administrative costs to implement will absorb any realized income.

DWC Waltb 5259
RECEIVED RECEIVED RECEIVED

11:30 AIRPORT
HOLIDAY
INW
CHECK MESSAGE

MEMO

August 30, 1976

To : Bob,
Fr : Peter Conlon
Re : Handi-capped Persons

Harvey Shapiro, who was Sen. Tunney's special Assistant in forming Legislation for the handi-capped would like to help draft papers. These papers would stress a national Handi-Capped awareness.

Shapiro has contacts Nation wide. He wants to help and is getting the run-around. Please contact him.

He also would like to arrange a press or media event if the Gov. would like while he visits California.

Please help this man, he wants to help. Harvey Shapiro - 213-277-4777

Peter
Peter

*Please see someone
helps him get touch
to consult w papers.*

September 26, 1978

Capt. Robert F. Madden
407 Cynthia Lane N.E.
Vienna, Virginia 22180

Dear Capt. Madden:

Governor Carter has referred your September 20 letter to me as I handle the health care issues on the staff level during the campaign.

I appreciate your comments about the problems that exist for handicapped people. I am enclosing for your review Governor Carter's position on this issue.

If you have any additional ideas or information on this subject, please let me know. Again, thank you for your interest and support.

Sincerely,

Robert S. Havely
Health Issues Coordinator
National Issues and Policy

RSH:j

Enc.

Sept 20 1976

Governor

Dear ~~Mr~~ Carter (my apologies)

Your staff is probably aware of this, but I am writing in case they are not. We have had a lot going on discrimination against women and minorities. A relatively new hot issue that is getting hotter has to do with discrimination against the handicapped. It has had a lot of lip service in the past, but times are changing and militancy is growing.

There is a small Federal agency called the President's Committee on Employment of the Handicapped (PCEH). It is primarily a publicity outfit that doesn't accomplish much. But it is changing. It is paralleled in the States by Governor's Committees (One in Georgia, probably) that vary from quiescent to active. Each year the PCEH has a conference in Washington, in the spring. Last year, the President was scheduled to attend for the most significant event - recognition of an outstanding handicapped person. A thousand or so attend the conference, from all over the U.S. Reflecting change, many attendees are handicapped, which was not the case in the past.

Come time for the President to attend, and he sent the Secretary of Labor as a substitute. There was strong and very verbalized resentment that he couldn't take 1/2 an hour from "cares about Vietnam" - the excuse made for his absence - and

(2)

get all the way over to the Washington Hilton for the annual meeting of his Committee. There are 10,000,000 severely disabled people in the U.S. — close to 30,000,000 with some discernible handicap. They all have families & friends. There are many professionals who work with them. They consume 2+ billion dollars in special services. They are growing more militant. The Congress has enacted legislation in their behalf. The Administration's interests are elsewhere.

As I said, the President's absence was noted (the most vocal critic was from Iowa). The next day the Washington Post & Star had extensive coverage on the President's visit to the Apple Blossom Festival in Winchester Va (farther than the Washington Hilton) to crown his daughter Susan as ~~queen~~ queen of the festival. Those of us with an interest in the welfare of handicapped people were furious.

Next spring you may be the President. There may not be a PCEH conference next year because there is scheduled at the White House Conference on Handicapped Individuals. (If you ever use the term publicly, don't say "the handicapped". It is like saying "nigger". Handicapped people, individuals, persons, bitter still disabled people — are acceptable terms.) I have enclosed a brochure on the Conference. It will be a big

Why not Pick a State Conference & arrange to speak before it?

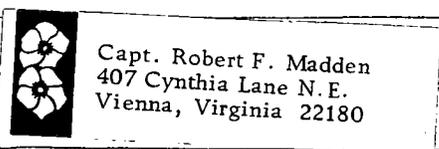
thing - especially if the President isn't busy in Winchester and unable to give it his personal support. Actually it is going on now. There are State conferences going on all over the country now leading up to the National.

I guess what I am suggesting is that it would be politically sound for you to make a public statement & take other actions calculated to assure the millions of voters ~~for~~ for whom the plight of handicapped people is a major issue that you place a high priority on this effort, will support it, listen to its recommendations and support their implementation - even if Winchester picks Army as the Apple Blossom Queen.

I have never before written a political candidate. On this issue, I have a handicapped child, my job at HEW has to do with employment of handicapped people (Sec. 501 of PL 93-112) which cause is getting minimal support, and I have been chosen as a delegate to the Virginia State Conference in November. My purpose in writing is to call your attention to a key issue - not to engage in partisan politics in violation of the Hatch Act.

Sincerely

R F Madden





report



July, 1976

4001 West Devon Avenue
Chicago, Illinois 60646
(312) 282-8787

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Adults

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Association

Our Bicentennial Message

With your indulgence we wish to depart from our practice of presenting newsworthy items and devote this space to a once in our lifetime celebration of the founding of our Country.

This historic event arouses, in us all, such bittersweet thoughts of the past and genuine hopes for the future that its basic significance transcends the use of mere words. The eloquent expressions of national purpose and instances of profound total commitment and personal sacrifice which resounds throughout our history renders an attempt to capture the true spirit of the moment almost beyond our means. And yet, with a sense of conscious pride in the fundamental principles that have been preserved over two centuries, and an all-too-painful knowledge of the unmet needs that demand a just and effective resolution, we take this opportunity to honor our great Nation.

On the occasion of this bicentennial year, we should pause and reflect on the social, moral, and spiritual fibers that have bound this Country together. Through the lessons of the past we must rededicate our energies and efforts toward a future of self-fulfillment and the realization of maximum human potential for the generations to come. We cannot hope to continue to aspire to the levels of accomplishment for our society without creating an environment that frees us from man-made barriers, and removes the obstacles that emanate from any system that underestimates the true capabilities of its people. Full and equal opportunities must be placed within the reach of everyone so that not only will it result in the obvious rewards of personal dignity, productivity, and happiness, but also in a broadening of the human resources that are necessary to the meaningful growth of our Country. The seemingly overwhelming pressures that dictate an ever changing placement of national priorities must be realistically faced as a challenge to our creative ability to articulate unmet needs, and respond with decisive results-oriented endeavors. The ultimate goal of improving the quality of life must remain in sharp perspective, and the methods employed to reach these heights must contain all of the relevant ingredients necessary for success.

Nowhere in the world is there a better place to accept and meet the responsibilities that lie before us. Armed with the heritage and creed embodied in the words, "with liberty and justice for all", we hold in our minds and our hands the capacity to make this a living reality. Now is the time to make our indelible contribution to those precious and inherent values which stand as the pillars of this Country's strength.

Happy Birthday America, and many happy returns to everyone.

1776 - 1976



the
national
newsletter

The White House Conference on Handicapped Individuals

Summer 1976

State White House Conferences

New Jersey was the first to hold a State White House Conference and the format reflected the individuality that characterizes State activities. New Jersey's conference, began June 26, and was convened at North Branch. It was the first of six regional conferences held across the State.

"We have, in establishing the White House Conference, provided flexibility for States to conduct conferences in ways that will meet State needs," said Jack F. Smith, Executive Director. "Some States will hold several regional meetings leading to a State Conference, while others will hold just one meeting. New Jersey, on the other hand, has a completely different approach. In the final analysis it is the results that count."

The White House Conference on Handicapped Individuals is relying on the deliberations of all the State Confer-

ences to provide the format for the National Conference. The information contained in each State report will be studied and used to set priorities.

Consumer action is the major thrust of the White House Conference on Handicapped Individuals. The State Conferences will provide consumers with their first opportunity to voice their needs and problems in order to evolve a national assessment leading toward solution-making action. The agenda of the State Conferences is to specifically allow for listening to the consumer.

Continued on page 3



Congressmen Albert H. Quie (R-Minn.) and John Brademas (D-Ind.) meet with Jack F. Smith, Executive Director, White House Conference on Handicapped

Individuals, to discuss extension of the date of the Conference. Subsequently date was extended.

Mission Statement

The mission of the White House Conference on Handicapped Individuals is comprised of three goals:

- To provide a national assessment of problems and potentials of individuals with mental or physical handicaps;
- To generate a national awareness of these problems and potentials;
- To make recommendations to the President and Congress which, if implemented, will enable individuals with handicaps to live their lives independently, with dignity, and with full participation in community life to the greatest degree possible.

The White House Conference on Handicapped Individuals thanks the President's Committee on Employment of the Handicapped for underwriting this newsletter.

Dear Dr. Menolascino:

Your letter of Sept. 7 just came to my desk. I'm sorry for the delay. It's always easy to blame the post office, but it could just as easily have been our own distribution system.

In any event, the deadline for answers to your questions is past. And, even if you could extend the deadline, I'm afraid the chances of our providing answers are pretty slim. Just now the Issues staff ~~is~~ is completely swamped with the work incident to ~~preparing~~ campaign speeches and, especially, the upcoming debates.

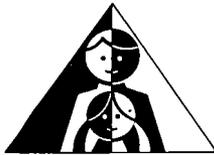
I'm sorry we weren't able to be of more help, but I know you'll appreciate the problems we face--as we appreciate your interest in the ~~the~~ Governor's campaign.

~~Sincerely,~~

I'm sure I don't need to explain (since I'm sure you're familiar with Governor Carter's record as it relates to the problems of the ~~hand~~ retarded in Georgia) that none of the above points to a lack of concern about the issues raised in your questions. They are urgent questions which deserve urgent ~~answers~~ answers. I am confident that Governor Carter, as President, will work closely with the Association.

sincerely,

jer ry



Gerry

national association for retarded citizens

GOVERNMENTAL AFFAIRS OFFICE

THE FEDERAL BUILDING • 1522 K STREET, N.W., SUITE 516 • WASHINGTON, D.C. 20005 • (202) 785-3388

Tony Orlando
National Honorary
Chairman

Frank Menolascino, M.D.
President

Philip Roos, Ph.D.
Executive Director

September 7, 1976

Governor Jimmy Carter
c/o Mr. Jody Powell
Carter for President
Box 1976
Atlanta, Georgia 30301

Dear Governor Carter:

The National Association for Retarded Citizens is the major national organization concerned with improving the lives of our nation's six million mentally retarded citizens. The role of the federal government in providing services to mentally retarded persons is critical and, over the years, has made available many opportunities for retarded persons to lead more productive lives.

The more than 300,000 members of our organization, representing 1,800 local organizations in our fifty states, are vitally interested in your stance regarding programs for mentally retarded persons. We would be greatly pleased if you could answer the attached questions so that our members could be informed as to your positions on several key aspects of our concerns. It would be very helpful if we could receive your answers by September 17, 1976, to enable us to include them in our national publication, MENTAL RETARDATION NEWS, which has a circulation of approximately 220,000. Please use the above address for your response.

We thank you very much for your kind cooperation and wish you the best of luck in your campaign.

Sincerely yours,

Frank J. Menolascino, M.D.
President

FJM:SF
Enclosure
cc: Robert Havely



FORMERLY THE NATIONAL ASSOCIATION FOR RETARDED CHILDREN

MANNY FERNANDEZ
HONORARY SPORTS CHAIRMAN

**OFFICERS AND EXECUTIVE
COMMITTEE**

FRANK J. MENOLASCINO, M.D.
President
University of Nebraska Medical Center
424 Dewey
Omaha, Nebraska 68105

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Minneapolis, Minnesota 55402

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MRS. MOONYEEN WEISS
Vice-President, South Central Region
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Houston, Texas 77055

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Gary, Indiana 46408

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Member-at-Large
Department of Psychology
Research School in Mental Retardation
Florida State University
Tallahassee, Florida 32306

DEAN MITCHELL
Member-at-Large
Farm Bureau Insurance Companies
5400 University Avenue
West Des Moines, Iowa 50265

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JERRY B. WILLIS

JOE WINTERS

MISS JULIE PARSONS
Youth NARC President

MRS. TERRELL DOUGAN
Director-at-Large

PETER LEIBERT
Director-at-Large

MISS KATE RODEN
Director-at-Large

NARC Twenty-Seventh Annual Meeting

October 19 – 22, 1976

Indianapolis, Indiana

Host: Marion County Association for Retarded Citizens

1. For the most part, categorical programs which are clearly intended to specifically assist mentally retarded persons provide the services so essential for mentally retarded persons to function in society. Some recent legislative proposals would subsume these programs in broad, block grant programs intended to meet the needs of many persons. What is your position regarding categorical programs to meet the specific needs of the handicapped vs. block grant programs? How can mentally retarded persons be assured of continued and expanded federally-funded services under any block grants?

2. Our organization has been greatly concerned over the years regarding overcrowded, inadequate and sometimes inhuman treatment of mentally retarded persons in institutions. The Department of Health, Education, and Welfare published regulations in 1974, establishing standards for residential facilities housing mentally retarded citizens financed by the Medicaid ICF/MR program. These standards, adapted from standards developed by the Joint Commission on the Accreditation of Hospitals, are intended to provide humane care and treatment in a safe environment. Do you support the enforcement of these standards and how can the federal government assist the states in compliance?

3. In 1975, the Congress passed the Education for All Handicapped Children Act. A major provision of this Act is an escalating federal commitment to finance expensive educational programs for handicapped children. Do you support the funding of the Education for All Handicapped Children Act at the full authorization levels through 1982?

4. Deinstitutionalization, a major thrust to provide community residential facilities and supportive services, as well as to improve institutional programs, is currently an HEW priority. What are your plans for the federal government to expand mental retardation services in the community and to improve institutional housing for mentally retarded citizens?

5. One of NARC's firmest objectives is to reduce and, eventually, to fully prevent mental retardation. Research and prevention programs are vital to carry out this goal. How will your administration approach this goal?

September 29, 1976

Isidore Kelsch
415 Beverly Road
Brooklyn, New York 11218

Dear Mr. Kelsch:

Thank you for your letter of August 2. I apologize for taking so long to reply. Governor Carter has referred it to me as I will be handling health care issues on the staff level during the campaign.

I appreciate your interest in the problems faced by handicapped and disabled people. I would appreciate your sending along your ideas and suggestions.

For your information I am enclosing a copy of Governor Carter's position paper on the issues.

Thank you again,

Sincerely,

Robert S. Hovely
Health Issues Coordinator
National Issues and Policy

CONTACT STA EINSTATS
WITH my ISSUES DEBIT

237-3397

325-0880

Howard E. Ull

Dot Padgett; add to list of
disabled folder: Wm. Sps.

Mr. Isidore Kelsch
415 Beverly Road
Brookly, N. Y. 11218

August 2, 1976

Governor Jimmy Carter
Plains, Geogia 31780

Dear Gov. Carter,

I have read in the papers that your aides in attempting to broaden your appeal, have mentioned a speech on the Handicapped.

A speech is not enough. A definite program is needed to alleviate the plight of at least 25 million disenfranchized Blind, Handicapped and Disabled U.S. Citizens and human beings of all ages.

I have many ideas on the subject which I have tried to present to such persons as Congressmen, Senators, Governors, etc. because they are in a position to do something about it. I have gotten nowhere.

What are you willing to do about it?

I would be willing to share my thoughts on the subject with you or anyone you may designate.

Sincerely yours,

Isidore Kelsch



Suite 406 • 1828 L Street, N.W. • Washington, D. C. 20036 • (202) 293-2930

September 29, 1976

Mr. Robert Havely
Coordinator
Health Task Force
Issues Department
The Carter-Mondale Campaign
P. O. Box 1976
Atlanta, Georgia 30301

Dear Mr. Havely:

We at the Epilepsy Foundation of America have read with great interest the Carter-Mondale issue paper dealing with Americans with disabilities. In the past, Governor Carter has supported the aims of the epilepsy movement by his willingness to proclaim epilepsy month, his support of the work of our Georgia Chapter and the warm reception he gave to our National Poster Child during the period when he was Governor of Georgia.

We applaud Governor Carter's interest in the White House Conference on Handicapped Individuals, and his commitment to study the recommendations of the Conference carefully.

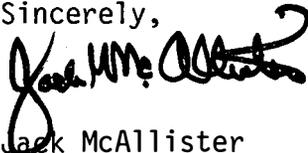
As you may be aware, a nine-member National Commission for the Control of Epilepsy and Its Consequences was authorized under the Health Services Act of 1975. The National Commission has been appointed and is now hard at work conducting national and regional hearings to determine the problems faced by people with epilepsy and the degree to which their very specific social and medical needs are being met. The next phase of the Commission's work is to research and prepare specific recommendations designed to alleviate these problems. A final report of the Commission is scheduled to be presented to the Secretary of Health, Education, and Welfare in the Spring of 1977.

As you may also be aware, the Epilepsy Foundation of America is the national voluntary health organization dedicated to the immediate control and eventual eradication of epilepsy as a health problem to the millions of Americans affected by the disorder. The Foundation, through its volunteers and members throughout the country, strongly supported the creation of the National Commission and anticipates major advancements in the control of epilepsy as a result of the recommendations contained in its final report.

Mr. Robert Havelly
Page 2
September 29, 1976

Therefore, we feel that it would be appropriate for the Carter-Mondale campaign to make a commitment, similar to that made to the White House Conference on the Handicapped, to carefully consider recommendations made by the National Commission on the Control of Epilepsy and Its Consequences. The volunteers and professionals in the epilepsy movement would be deeply appreciative of Governor Carter's continued interest in the problems of epilepsy.

Sincerely,

A handwritten signature in black ink, appearing to read "Jack McAllister". The signature is stylized and cursive, with a large, sweeping flourish at the end.

Jack McAllister
Executive Director

JMCA/cb

JIMMY
CARTER

WALTER
MONDALE



Leaders, for a change.

October 27, 1976

Mr. Jack McAllister
Executive Director
Epilepsy Foundation of America
Suite 406
1828 L Street, N.W.
Washington, D. C. 20036

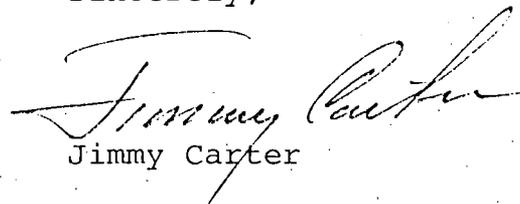
Dear Mr. McAllister:

Thank you for your letter of September 29 to my staff, in which you discussed the work of the National Commission for the Control of Epilepsy and Its Consequences. As you know, I have had a long and continuing concern for the problems of epilepsy, and a deep interest in finding needed solutions.

The Carter-Mondale campaign has an intense interest in the problems facing Americans with disabilities. We have studied the weaknesses and failures in existing programs serving these citizens, and I pledge to make every effort to better serve our people with handicaps. One of the actions I have promised to take is to study carefully the recommendations of the White House Conference on Handicapped Individuals.

You may be sure that with my continued interest in epilepsy I will make a similar commitment to study the final report of the National Commission for the Control of Epilepsy and Its Consequences with a view toward implementing appropriate recommendations contained in it.

Sincerely,



Jimmy Carter

James

105 Oak Road
Warm Springs, Georgia 31830
June 28, 1976

546

The Honorable Jimmy Carter
Jimmy Carter Campaign Headquarters
1795 Peachtree Street
Atlanta, Georgia 30309

Dear Governor Carter:

In my communication of April 29, 1976, I pointed out the lack of interest on the part of both President Ford and President Nixon in serving the disabled and their lack of support of the Rehabilitation Services Administration. Since that time I have been in contact with our consultant on the Washington scene who has been kind enough to prepare for me detailed information on action taken by both the aforementioned as it relates to the Rehabilitation Act. Details enclosed.

During a three-day visit to Washington last week, it became apparent that the career federal employees have come to realize that Jimmy Carter will be the next President. They are convinced you will initiate reorganization in order to bring greater efficiency to government. Therefore, many are now attempting to gain additional power which they feel will enable them to deal from a position of greater strength once a reorganization is effected.

Attached is a document indicating the power struggle that is going on within the Office of Human Development which will result in diluting the strength of the Commissioner, Rehabilitation Services Administration, ignoring the intent of Congress.

Again, if there is any way you feel I can be of assistance, do not hesitate to ask.

Most sincerely,

Albert P. Calli

APCjdb

Enclosures

LAW OFFICES
FLEMING AND KREVOR
PROFESSIONAL CORPORATION

(202) 872-1033

June 11, 1976

HENRY H. KREVOR
JOE W. FLEMING II

SUITE 300
1730 RHODE ISLAND AVENUE, N. W.
WASHINGTON, D. C. 20036

514

Mr. Albert P. Calli
Executive Director
Georgia Warm Springs Hospital
Warm Springs, Georgia 31830

Dear Al:

At the ARF meeting, I promised to give you a summary of the Nixon-Ford record on rehabilitation for use by the Carter campaign.

The following will, I hope, hit the high points without being overly detailed.

The first Federal Rehabilitation Act was passed in 1920 with a focus on vocational rehabilitation of physically handicapped people. Since that time there have been refinements and expansions of the program to provide Federal funds to the states on a matching basis for rehabilitation services. This rehabilitation was never a partisan issue and indeed a number of the progressive steps were taken in this field during the Eisenhower Administration.

This non-partisan approach to rehabilitation of handicapped people came to an abrupt end with the election of Richard Nixon. On two separate occasions Nixon vetoed a new comprehensive rehabilitation services act which gave priority to services to the most severely handicapped and expanded the focus of rehabilitation from strictly vocational services to include rehabilitation for total life activities. President Ford followed suit in 1974 by vetoing amendments to the Rehabilitation Act of 1973.

The Vocational Rehabilitation Act of 1972 was a comprehensive bill which extended the basic authority for the rehabilitation program and also made a number of changes in the statute to make rehabilitation services more broadly

Mr. Albert P. Calli
June 11, 1976
Page Two

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This bill was passed without opposition by both Houses and the Conference report was adopted without opposition on October 14, 1972. Nixon pocket-vetoed the bill, thus shattering the long-standing policy of cooperation between the Executive and legislative branches with respect to rehabilitation legislation. The reason given for the veto was that the program should not be addressed to the needs of severely handicapped people without an immediate vocational goal and, of course, "fiscal irresponsibility" was also invoked.

This veto at the end of the Congressional session left the rehabilitation system of the country in a state of great confusion. The 93rd Congress took up a rehabilitation bill shortly after it convened and passed a somewhat less ambitious bill on March 15, 1973. Nixon promptly vetoed this bill again on the theory that it spent too much money on severely handicapped people.

As a result of arduous negotiations within the Administration and Congress, a diluted compromise measure, the Rehabilitation Act of 1973 (P.L. 93-112) was finally passed on September 26, 1973. In order to meet the Administration's objections, the Congress had to make several compromises from the original bill. They were:

1. reducing the authorization levels, and
2. eliminating the special categorical programs for the spinal cord injured, renal disease, older blind and deaf, and comprehensive rehabilitation services for the severely handicapped.

In 1974, Congress passed amendments to the Rehabilitation Act of 1973 which extended the authorization authority for one year, transferred the Rehabilitation Services Administration to the Office of the Secretary, strengthened the

Mr: Albert P. Calli

- June 11, 1976

Page Three

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The disruptive effect of these vetoes and the conflict between the Executive and legislative branches of government which they reflect cannot be overestimated. For a year, the state rehabilitation agencies were in a period of considerable confusion with respect to availability of funds and authority for expenditure of those funds. For a substantial part of this time the rehabilitation program operated on continuing resolutions, since there was no statutory authority for the program. This produced very uneven ineffective administration, and of course the beneficiaries of the program -- handicapped people -- bore the cost. For example, in 1974 the appropriations for the rehabilitation program were not included in the Labor HEW bill as it passed the House because there was no authority for the program due to the vetoes of the 1972 and 1973 rehabilitation bills. The Senate included rehabilitation appropriations and then the entire bill was vetoed. As a result, the program had to operate on a continuing resolution at a lower level. In FY'75 the Administration proposed to rescind \$30 million in rehabilitation appropriations. This was rejected by the Congress. In December of 1975 Ford vetoed the Labor HEW appropriation bill including rehabilitation appropriations. This veto was overridden by the Congress in January, 1976.

In summary, the Nixon-Ford position on the rehabilitation program is typical of its attitude on social programs in general, that is to hold the funding to a minimum and oppose any effort to broaden services.

I hope this is helpful. Let me know if you would like something else.

Sincerely yours,



Joe W. Fleming

JWF/blk

FACT SHEET

Issue Statement on Centralization of Grants Management Outside of the Rehabilitation Services Administration

The Problem

1. The Rehabilitation Act of 1973 as amended states that the "... Commissioner shall be the principal officer, of such Department for carrying out this Act. "... The functions of the Commissioner shall not be delegated to any officer not directly responsible, both with respect to program operation and administration, to the Commissioner.". Congress allowed that, as expressed by the conferees in the Joint Explanatory Statement accompanying the conference report on H.R. 14225 (H. Rep. No. 93-1457 and S. Rep. No. 93-1270), certain routine administrative services in support of RSA could be performed outside of RSA. However, it intended that the Commissioner retain responsibility for all decision/policy making authorities. The Commissioner, in this respect, may not delegate any decision/policy making function to staff outside RSA.
2. The Assistant Secretary for Human Development of the Department proposes to transfer out of RSA those functions which are decision/policy making in nature for project grant management including all authorities of the RSA Grants Management Officer and professional staff related thereto.
3. Listed below are those functions of the grants officer which are proposed for centralization outside of RSA. Removing these authorities and functions from RSA is a flagrant violation of the Rehabilitation Act and the responsibility therein of the Commissioner to perform or have performed those functions in the area of grants administration which are decision/policy-making or are so intertwined with decision/policy making as to be inseparable.
 - a. Performance of financial analysis on grant applications.
 - b. Assessment of applicant financial management capability.
 - c. Determination of application compliance with DHEW/RSA legislation, regulations and policies.
 - d. Negotiation of Cost Sharing and detail budget for the grant award.
 - e. Provision of technical assistance/interpretation of DHEW/RSA grants administration policies to RSA Central and Regional staff and grantees.
 - f. Monitoring of grantee business management performance and compliance with DHEW/RSA legislation, regulations and policies.
 - g. Analysis of RSA project grant financial commitments, forecast of obligations, etc.
4. In effecting this centralization of functions, the Assistant Secretary for Human Development of the Department is removing from RSA the authority to appoint a grants management officer and related support staff.

Contrary to the specific intent of Congress as to the prohibition against transfer of staff out of RSA, grants management staff responsible for the functions listed above have been transferred to the Office of Human Development.
5. A bureaucratic malady which was widely recognized nationally and which the Congress sought to correct with respect to RSA by the 1973 Act as amended was that the rehabilitation program had been submerged within SRS and consequently had suffered in terms of time devoted to the program, personnel assigned to the program, and program operation seems to have reoccurred through the violations of law as stated above.

1977 Appropriation Bill for HEW

GENERAL PROVISIONS

Limitations and Legislative Provisions

The following limitations and legislative provisions not heretofore carried in connection with any appropriation bill are recommended:

Office of Human Development:

Salaries and Expenses:

Funds appropriated under this heading for management and administration of the Rehabilitation Act of 1973 (as amended by Public Law 93-516) shall be used for carrying out Section 3. (a) insofar as "... the functions of the Commissioner shall not be delegated to any officer not directly responsible, both with respect to program operation and administration, to the Commissioner." With respect to centralization of certain routine administrative services by the Office of Human Development outside of the Rehabilitation Services Administration as expressed by the conferees in the Joint Explanatory Statement accompanying the Conference report on HR 14225 (H. Rep. No. 93-1457 and S. Rep. No. 93-1270);

Salaries and expenses shall be available for performing grants management functions outside RSA that relate only to the "... processing of the necessary grant documents required to implement an RSA decision to award a project grant." The RSA grants management officer and a related support staff of no less than eleven (11) shall be located only within RSA and perform such functions as defined by HEW Grants Administration Manual Chapter 1-03 that are not of a routine administrative nature such as policy development and implementation, technical assistance to grantees, grant negotiations and financial management.

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LAW OFFICES
FLEMING AND KREVOR
PROFESSIONAL CORPORATION

(202) 872-1033

June 11, 1976

HENRY H. KREVOR
JOE W. FLEMING II

SUITE 300
1730 RHODE ISLAND AVENUE, N. W.
WASHINGTON, D. C. 20036

Mr. Albert P. Calli
Executive Director
Georgia Warm Springs Hospital
Warm Springs, Georgia 31830

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Mr: Albert P. Calli
- June 11, 1976
Page Two

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Mr. Albert P. Calli
June 11, 1976
Page Three

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In summary, the Nixon-Ford position on the rehabilitation program is typical of its attitude on social programs in general, that is to hold the funding to a minimum and oppose any effort to broaden services.

I hope this is helpful. Let me know if you would like something else.

Sincerely yours,



Joe W. Fleming

JWF/blk

PHILIP A. HART
MICHIGAN

COMMITTEES:
COMMERCE
JUDICIARY

United States Senate

WASHINGTON, D.C. 20510

July 30, 1976

Mr. Lyle G. Taylor
15515 52nd Ave.
Edmonds, Washington 98020

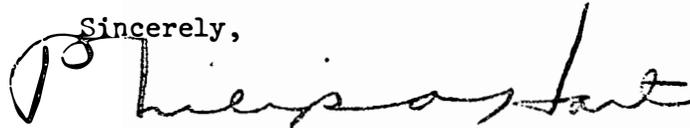
Dear Mr. Taylor:

Enclosed is the reply to my inquiry in your behalf,
which I have just received and which I hope will be
of assistance to you.

If you have any questions, or if there is further
inquiry I can make, be sure to let me know.

With best wishes,

Sincerely,



Philip A. Hart

Enclosure



VETERANS ADMINISTRATION
DEPARTMENT OF MEDICINE AND SURGERY
WASHINGTON, D.C. 20420



IN REPLY
REFER TO: 128

The Honorable
Philip A. Hart
United States Senate
Washington, D.C. 20510

JUL 22 1976

Dear Senator Hart:

We are pleased to respond to your inquiry in behalf of Mr. Mike Taylor.

Experiments conducted by Dr. William F. Windle, an American neuroanatomist, prompted Russian scientists to pursue studies on Central Nervous System (CNS) regeneration. Many American physicians, including some from the Veterans Administration, have had the opportunity of discussing their experiments with the Russian physicians who recently visited the United States.

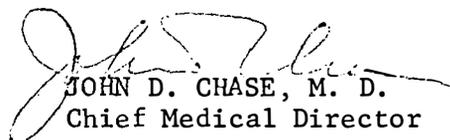
The Russian studies are along the line which Mrs. Taylor states in her letter but none of the statements made by the Russians are as optimistic as the statements which others impute to them.

We agree that the problem of CNS regeneration is one of medicine's greatest challenges and the Veterans Administration is very much concerned about this program. We hope to apply the fruits of recent and future basic science research on neural regeneration to spinal cord injured patients.

The Veterans Administration plans to contribute to the development of physician investigators in the basic neuroscience disciplines. The close affiliations that exist between many Veterans Administration health care facilities and university medical centers offer an opportunity to develop investigations directed toward regeneration as well as toward the clinical management of the problems of the spinal cord injured patient.

This is a very complicated problem. Research of the type requested by Mrs. Taylor is extremely costly, but allocation of funds alone will not achieve what we all hope for. When responsible investigators submit proposals to explore this important field, every consideration will be given to these proposals. The Veterans Administration believes that it can contribute by continuing its close affiliations with university medical centers and other research groups which have the necessary personnel and facilities.

Sincerely yours,


JOHN D. CHASE, M. D.
Chief Medical Director

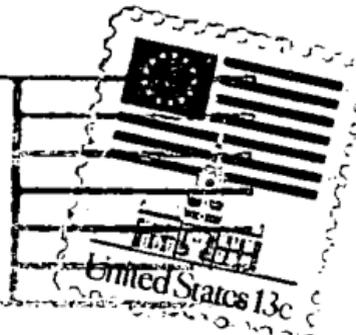
Enclosure

Show veteran's full name, VA file number, and social security number on all correspondence.

Arthur Greenough
2100 Bloomington Av. S. 122
Mpls. Mn. 55404



CONQUER
MULTIPLE
SCLEROSIS



Issue

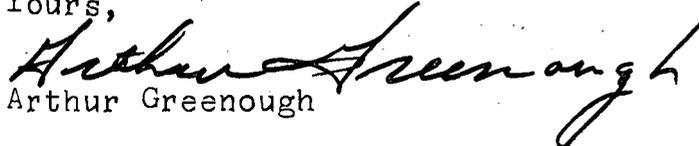
Jimmy Carter,
Campaign Head Quarters,
Atlanta, Ga. 30301

June 7, 1976

Mr. Jimmy Carter,
Sir,

It would seem, Sir, that you are, at this time, almost assured of the nomination of the Democratic Party, for the office of President of the United States. If you get this nomination, and win the office, what are your intention toward the needs of the handicapped? And, in the nature of a suggestion, what do you think of the inclusion of a handicapped person to a position in the cabinet of the president. It does not matter if the person is man or woman, just so this person is a member of the handicapped community of the U.S.A. Another suggestion would be a person like Miss Jamie Becker, of St. Paul, Minnesota. Jamie is a good party member, but she would also understand the problems of the handicapped. I hope that you can see fit to think this one over. Sir.

Yours,


Arthur Greenough

Arthur Greenough
2100 Bloomington Avenue South, #122
Minneapolis, Minnesota, 55404

The Reverend Ronald Dean Rostin
205 Indiana Avenue
Iowa Falls, Iowa 50126

March 27,th 1976

Mr. Steven D. Stark, Issues Coordinator
Jimmy Carter for President Committee
P. O. Box 1976
Atlanta, Georgia 30301

Dear Mr. Stark:

I want you to know that I endorse
Governor Carter. I feel that he is what
America needs so desperately!

I have a special concern. Like many
thousands of my fellow Americans I
have a physical handicap. I was very
fortunate to have a chance for a
good education. But many are not so
fortunate. And employment, housing,
even entrance to buildings are "shut"

March 27, 1976

- 2 -

Mr. Steven D. Stock
Atlanta, Georgia 30301

to persons who may have physical handicaps

I have a seminary degree but with a physical handicap (mild, spastic cerebral palsy) I am having difficulty finding a pastorate. I am finding most Churches reluctant to accept even a minor physical handicap in a pastor or an associate pastor.

My resume for your consideration is enclosed. Can you be of any help.

Thank you for your time.

Sincerely,

Ronald Dean Rankin

NATIONAL REHABILITATION ASSOCIATION

MEMBERSHIP COMMITTEE
1522 K STREET, NORTHWEST
WASHINGTON, D.C. 20005
(202) 659-2430

March 16, 1976

The Honorable Jimmy Carter
Jimmy Carter Presidential Campaign
P. O. Box 7667
Atlanta, Georgia 30309

Dear Governor Carter:

I noted with interest your candidacy for President of the United States of America. The American people will be voting in a particularly significant election in this Bicentennial year.

The National Rehabilitation Association has a primary concern in programs, appropriations, and legislation that affects the lives of disabled and handicapped persons. Although I realize that you and your staff are asked to respond to numerous issues, I would find it most helpful if you would address yourself to a few items of basic concern to our national organization. These specific issues are:

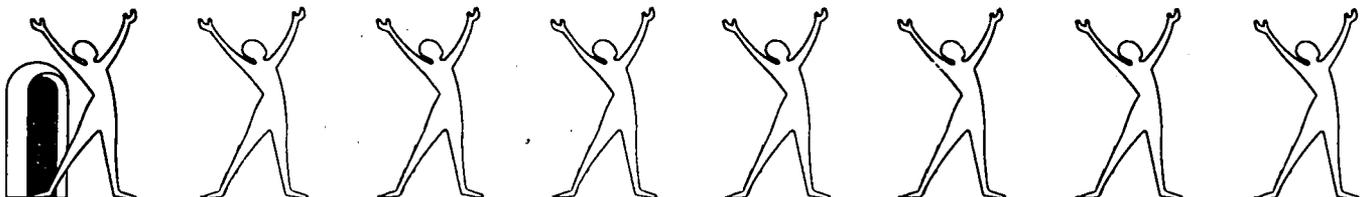
1. Extension of the Rehabilitation Act of 1973 (PL 93-112)
2. National No-Fault Health Insurance
3. Enforcement of Section 50 of the Rehabilitation Act (PL 93-112)
4. Position on Section 101 of Title I (PL 93-112) which specifies "(A) designate a State Agency...."

I thank you for your time, thought, and effort in responding to these issues. Your stated positions will be extremely valuable in compiling data to inform our membership as to the political climate and interest regarding handicapped and disabled Americans.

Sincerely,

Michael R. Clowers

Michael R. Clowers, Ph.D.
President, Puget Sound Chapter,
National Rehabilitation Association
16225 - 37th Avenue N.E.
MRC/mc Seattle, Washington 98155





Center for Independent Living, Inc.

2539 TELEGRAPH AVENUE • BERKELEY, CALIFORNIA 94704 • (415) 841-4776

June 8, 1976

Jimmy Carter for President
Campaign Headquarters
P.O. 1976
Atlanta, Georgia 30301

Dear Sir or Madam:

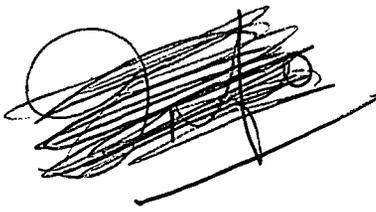
I was referred to your office by the Mary King Associates of Washington, D.C. as the source of material relating to Jimmy Carter's stand on issues relating to disability.

I would appreciate copies of any information pertaining to disability which could be made available.

Sincerely,

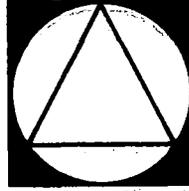
Judy Heumann
Deputy Director

JH/bm



ISSUES
disabilities

Room 308, 1346 Connecticut Avenue, N.W. • (202) 785-4265
Washington, D.C. 20036



American Coalition of Citizens with Disabilities Inc.

July 9, 1976

Mr. Jimmy Carter
Carter for President
1784 Peachtree Street, N.E.
Atlanta, Georgia 30301

Dear Mr. Carter:

It is pressing in this election year that the rights and needs of the disabled community be given careful consideration and support. The American Coalition of Citizens with Disabilities, along with many other concerned groups and individual consumers, is greatly interested in becoming familiar with your specific positions with respect to the disabled. For the purpose of our enlightenment, and with an eye towards the upcoming campaign, we ask you to please comply with the following two requests:

1. Please send us fifteen copies as soon as possible of a one page statement in which you detail your position on issues relating to people with disabilities. We plan to mail your statement, along with the comments of the other candidates who respond, to organizations for the disabled and to the editors of the many consumer publications that they publish. It should be noted that we will mention the names of those candidates who did not respond to our request.
2. Please send six copies of any and all position papers that you have developed which relate to issues of concern to the disabled. We hope that these will include a wide variety of issues, including such areas as education and employment opportunities. We will analyze these statements carefully, and our assessment, again, will affect our role in the Presidential campaign in the coming months.

We are enclosing a copy of our policy statement for your consideration. Thank you for your time. We expect to hear from you shortly and hope that you realize the importance of the issues which concern people with disabilities.

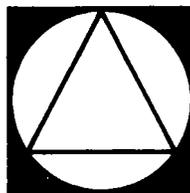
Sincerely,

Eunice Fiorito

Eunice Fiorito
President
AMERICAN COALITION OF CITIZENS
WITH DISABILITIES

EF/mb

Room 308, 1346 Connecticut Avenue, N.W. • (202) 785-4265
Washington, D.C. 20036



American Coalition of Citizens with Disabilities Inc.

STATEMENT FOR U.S. PRESIDENTIAL CANDIDATES

The American Coalition of Citizens with Disabilities is a national coalition composed of national, state and local organizations of disabled people and their advocates. The combined membership represents 28 million American citizens of the nation. The basic purpose and focus of the ACCD is to assure participation in the mainstream of life for all disabled citizens, to promote their social well-being and to assure the full exercise of the human and constitutional rights of citizens with disabilities.

The major concern of the ACCD is the failure of the United States to implement the laws passed by present and past legislators and Administrations. Such a failure has led to inadequate understanding, a lack of awareness and sensitivity, and too much neglect by governmental agencies serving all American citizens. Too often, regulations are delayed, are inadequately funded, and result in ineffective and insufficient implementation. In particular, we speak to the problems in implementing the Civil Rights provisions of Section 503 and 504 of the Rehabilitation Act of 1973, laws to remove architectural barriers, inadequate benefits for paralyzed veterans, and lack of alternatives to institutionalization of individuals. These are examples of how the United States has failed to make a firm national commitment to its disabled citizens.

The Rehabilitation Act of 1973 as amended provides for the holding of a White House Conference on Handicapped Individuals. This conference will be held in 1977. The ACCD, its organizations and members, have been fully involved in the planning of this conference. We look forward with anxious anticipation to the recommendations arising from this occasion and to their implementation. It is the responsibility of private citizens and agencies to prod the nation and the government to implement such recommendations.

The ACCD is in a strategic position to provide continuing consumer direction and analyses to the White House and to other governmental agencies in developing programs for implementing White House Conference recommendations.

Specifically, we are seeking the following reactions and commitments from Presidential candidates:

1. That each candidate develop and articulate a short position statement regarding his views on programs currently mandated by law that are specifically designed to impact on disabled citizens.
2. That each candidate state his position on carrying out the recommendations of the White House Conference on Handicapped Individuals and on the extent to which the ACCD will be utilized in these efforts.
3. That each candidate, if nominated by his party, participate in a press conference sponsored by ACCD where he will further announce to 28 million disabled Americans what efforts will be made during his administration, if elected, to achieve equality in all areas of life where the federal government exerts control through programs within the Executive Branch.

Prepared by

Eunice Fiorito
President
AMERICAN COALITION OF CITIZENS
WITH DISABILITIES

EF/mb
7/9/76

3375 Alma Street, Apt. 358
Palo Alto, California 94306

June 20, 1976

Mr. David E. Moran
Issues Staff
Jimmy Carter Presidential Campaign
P. O. Box 1976
Atlanta, Georgia 30301

Dear Mr. Moran:

Re: Your letter of May 19 (postmarked June 15; received June 18)

Something must have been omitted with your letter. Two things lead me to this assumption: 1) 24¢ was used to send less than one ounce; 2) only two items of "information on Governor Carter's record in helping the handicapped" were enclosed. You surely don't think that ~~"Special Education" and "Warm Springs"~~ are enough to make any physically handicapped person want to vote for Jimmy Carter. What about housing, employment, transportation, and access to public buildings? Don't you think that what constitute civil rights for blacks are also civil rights for the disabled?

Does Mr. Carter want civil rights only for those with political clout? Or does he think that the physically handicapped are also mentally handicapped? He certainly does have a problem defining words, as TIME (June 21) reported. Perhaps he is trying to say, like another egghead (Humpty Dumpty in Alice in Wonderland), that this is a topsy-turvy world and the discipline of language is irrelevant. Be that as it may, what you sent does not impress me nor will it, I am sure, impress other members of the California Association of the Physically Handicapped.

Sincerely,


Jo Guttadauro

PS. Humpty Dumpty's exact quote--perhaps Mr. Carter's speechwriter could confirm this--is: "When I use a word, it means just what I choose it to mean--neither more nor less."



HUMANE PRIORITIES

FEDERATION OF PARENTS ORGANIZATIONS For The New York State Mental Institutions Inc.

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Northeast Nassau Psych. Ctr.
Mr. Irving Tuchfeld
Pilgrim Psychiatric Ctr.
Mrs. Pauline Altman
Queens Childr's. Psych. Ctr.
Mrs. Erma Gordon
Rochester Psych. Ctr.
Mr. Milton D. David
Rockland Childr's. Psych. Ctr.
Mrs. Gregory A. Foti
Rockland Psych. Ctr.
Mr. Irving Berkowitz
Rome Develop. Ctr.
Mr. Stewart O. Howe
Sagamore Childr's. Psych. Ctr.
Mr. John Behnken
Sheridan Service Center
Mrs. Helen McCarthy
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Willoughbrook Develop. Ctr.
Mrs. Diana McCourt

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Service: (212) 765-7488

July 12, 1976

Hon. James Earl Carter II
Plains, Georgia 31780

Dear Governor Carter:

It is certainly not news that human services delivery has suffered because of the serious economic recession that has fiscally strangled a large segment of this country. The high unemployment in major areas and the resultant reduction in tax revenues is well known.

Strangely enough, a resolution to the unemployment dilemma can also remediate other social problems and become a self liquidating proposition, as was the G.I. Bill and other self help benefits provided by the Federal Government in times of need.

The social problems alluded to are the Architectural Barriers that prohibit egress and/or access, or do so by insulting the dignity of our fellow citizens with physically handicapping conditions. These barriers exist on our streets and sidewalks (curbs), in public and private buildings, in schools, libraries, houses of worship, clinics, places of commerce and industry, parks and recreation, not to mention buildings designed to provide entertainment to the masses and the social elite alike. Add to this, public transportation and the picture is complete.

Of what value is life if one is deprived of the ability to move about, make use of facilities, gain an education and utilize that education as a productive citizen? Yet millions of our fellow citizens are so deprived because of a physical condition that mandates their confinement to a wheel chair or other limiting prosthesis. They are caught in the "Catch 22" of the desire and ability to participate and become productive, or expand their productivity on the one hand; yet being forced on the public dole or being made objects of pity and charity on the other.

While the removal of architectural barriers is shouted as a "cause celebre" across this land, the construction trade and related workers remain idle, among

ASSOCIATED GROUPS:
Buffalo Community M.H. Ctr.
Health Advocates, Inc.
Fairmount Childr's. Ctr.
F.O.R.M.H. Foundation
N.Y.C. Coalition for Comm. Health
Rise East Concerned Parents
Voice for the Handicapped
Camp Venture, Inc.

the highest percentage of unemployed, nationally. The solution, therefore, with all of the economically beneficial ripple effects, is obvious, yet President Ford vetoes a bill that will make possible \$1.75 billion dollars, to put tens of thousands of unemployed citizens back to work.

What I am proposing, for your consideration, is for you as a Presidential Candidate, and if elected as President, to give meaning to the Federal dollars. To insist that they not just be used to employ people in "makework" projects, or for local government to pad their payrolls with patronage paid for with Federal funds. The public works program designed to get the construction and related trades back to work, should be aimed at those major urban and suburban areas to remove the architectural barriers, beginning in public buildings and extending to curbs, and ultimately, the private sector.

By an interesting coincidence, the areas of high unemployment also contain the largest population of people with physical disabilities, and the most significant architectural barriers to the public and private sector. Everything from Universities to Post Offices.

I have attempted for over one year now to get this proposal seriously considered by the Ford Administration. Somehow they are content to build expensive bombers and other weapons of dubious value, while human lives and the potential for building a better world, go ignored or overlooked.

If this country chooses to put human services at such a low priority, what is it that we will have to defend? What a fabulous opportunity thus presents itself to dedicate the beginning of the Tricentennial to that noble experiment begun 200 years ago, that all (not just able-bodied) people are endowed by their Creator with the right to Life, Liberty and the Pursuit of Happiness.

Finally, allow me to present to your campaign, a slogan which, if followed, will certainly redirect this country in the direction you have articulated thus far. "For all of our citizens, the right to be respected for the dignity of their humanity."

Respectfully yours,



MORTON POSNER
Executive Director

MP/s

CC: American Coalition of Citizens with Disabilities
Suffolk County Architectural Barriers Committee
Association for a Better Community for Disabled
Disabled in Action

Unnecessary Barriers for the Disabled

By JOYCE MAGID

THE car pulls up at the curb and stops. The driver, Mary Ann Sciacca of Commack, pulls her front seat forward, reaches to the back of the car, and slides her wheelchair out. Then, she unfolds the chair and locks it in place. Sliding across the front seat, she carefully lifts herself into the chair. She hooks the leg rests onto the chair, then places her legs into position on the rests. She reaches into the car for her purse, closes and locks the door and maneuvers toward the supermarket. Only then does she notice the poles in front of the store that keep the carts in and the wheelchairs out.

These poles, constructed by people insensitive to the physical limitations of a person in a wheelchair, prevent Miss Sciacca from entering the store. Confined by polio to a wheelchair since she was 11 years old, Miss Sciacca is one of the millions of Americans daily facing similar situations. Ignorance and lack of public awareness have fostered discrimination against that segment of society, fully 10 percent of our population, physically different from what is considered the norm. These people, termed "disabled," may be senior citizens, have severe arthritis, a heart condition, neuromuscular disorders, visual and hearing loss, and are often on crutches or in wheelchairs.

Many disabled persons have learned to emotionally and physically accept their body's limitations. Some can even cope successfully with the condescension and prejudiced attitudes of other people. However, they are totally unable to overcome the architectural barriers constructed by our society that prevent them from living full and active lives.

What are architectural barriers and what do they mean to Miss Sciacca and millions of other disabled people?

You must imagine what an average day's activities would be like for you if you were in a wheelchair to fully appreciate this exercise in frustration.

The first stop, at a shopping center, has no specified parking areas for the disabled, and after maneuvering your wheelchair between the narrow parking spaces and the busy lot you find you cannot pass the wheelchair through the shopping-cart poles and thus cannot enter the store.

The next stop is at church. The long row of steps leading to the door makes access to the church completely impossible.

A trip to a public library reveals that the facility is accessible,

but once inside, you discover you cannot utilize much of the library because of the many steps leading down to the reading rooms. These buildings are not unique, and exist in abundance in every community and township on Long Island.

Your final stop, at Islip Town Hall, will provide the only successful experience. The building is now completely accessible: wide parking spaces; ramped curbs; wide entrance doors, low water fountains and telephones; well-designed lavatories. Islip, in addition, is the only township on the Island with its own Department of Handicapped Services, and special car stickers allowing emergency parking in unauthorized areas.

A campaign is gaining momentum in Suffolk County aimed at removing architectural barriers from buildings and thus making them accessible to all people. Working in conjunction with the Human Rights Commission, Miss Sciacca is presently a complainant in a court case charging five Long Island stores with discrimination against disabled persons. On the basis of the addition, in 1974, of the term "disabled" to the State Human Rights Law, Miss Sciacca has brought suit against these businesses, all of which have barriers that render the store inaccessible to the disabled. As chairperson of the Suffolk County Architectural Barriers Committee, an organization of disabled and nondisabled persons, Miss Sciacca is working to influence legislation.

This is just the beginning. Public awareness and public pressure are the keys to changing existing architectural barriers and preventing further restrictive construction. If you see a store, parking lot or bathroom that is inaccessible, complain to the owner. Write a letter, describing the poor designs of buildings and streets to your town supervisor, department of public works or highway department, insisting that these barriers be removed.

"In many areas of their lives, disabled people might as well be dead," Miss Sciacca says. "They are disabled and things are closed to them." Your awareness can help open Long Island to thousands of your forgotten neighbors.

Joyce Magid, a writer who lives in Melville, is a member of the Suffolk County Architectural Barriers Committee.



STOP BEING A 2nd CLASS CITIZEN
COME ALIVE AGAIN VOTE IN '76

THE OLD FOLK'S LOBBY No. 12

1159 South 11th Street
Beaumont, Texas 77701

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TOO MANY, EQUAL JUSTICE SIMPLY DOES
NOT EXIST, AND THE VERY FOUNDATIONS
OF OUR LIBERTY HAVE BECOME THEIR
WAILING WALL!!!

Mr. Jimmy Carter,
2000 P Street, N W.,
Washington, D. C. 20036.

Newsletter for May 1, 1976

Dear Mr. Carter:

This is an ordinary snapshot of the right leg that was needlessly crippled on the Medicare Merry-Go-Round, after TWO YEARS of treatment and therapy. It will never regain the size or strength that was lost, and I now walk with a limp and a stick, and must place the foot just so to keep the bum knee from dumping me on the ground, and at age 72, I am still perfectly healthy and active otherwise, but my retirement has been ruined, forever.

It is easy to see why it will never be forgotten or forgiven, and why I have been fighting a battle, single-handed, armed with only a Social Security Check, that most of the Presidential Candidates, with their millions of dollars, have been so afraid to even mention, they have thrown away their only chance to be elected because they lack the courage to come right out and say: "America is being suckered, and our Social Security Program is being bankrupted, and our poor and our old are being TREATED WORSE THAN TRASH by the people who are grabbing the money, and it is time to DO SOMETHING ABOUT IT!", but if my efforts will keep just ONE PERSON from having to endure the suffering and neglect, the abuse and degrading treatment I had to endure as a Medicare patient, I will consider every minute, and every penny, well spent!

It is time for every candidate to realize that \$200.00 a month people like me, who are trying to live in a \$1000.00 a month society, and all the other millions of Americans who are now hard pressed trying to pay the Nation's bills, will have little interest in foreign exchange, the stock market, what the Arabs buy or the oil imports, the balance of payments or the price of aircraft, just who will help who, or who will fight where. Not one of these things will now elect a President of the United States.

ONLY WE CAN DO THAT, and in 1976, we only have time to worry about US!!

Most Sincerely Yours,

Marshall Cline
Marshall Cline.

STOP BEING A 2nd CLASS CITIZEN
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SIMPLY DOES NOT EXIST, AND THE VERY FOUNDATIONS
OF OUR LIBERTY HAVE BECOME THEIR WAILING WALL!!!

Mr. Jimmy Carter,
2000 P Street N W.,
Washington, D. C. 20036.

Newsletter for April 1, 1976
(Delayed waiting for pictures)

Dear Mr. Carter:

This effort is being made in behalf of every Senior Citizen in America, who like myself, worked for half a lifetime supporting Social Security, and during most of this time it took a full 6 day week and lots of overtime to earn what is one day's pay today, so we do not think anybody is GIVING us anything, except the dirty end of the stick when we seek the medical care we paid for, years in advance, and now we are in trouble, and my 18 months of research have given me the insight that has made every prediction of this Lobby since last August, correct to date.

Every other segment of our society can fight against such injustice with a strike, a demonstration or whatever, and against such exorbitant prices in everything else but medical care with a refusal to buy, but how can we fight against the very things that mean life itself except with a vote at election time. The doctors can strike to get what THEY want, but all we can do is go to Washington for the help that HAS NOT been forthcoming, so I fully expect this issue to be a deciding factor in the elections of 1976.

America soon expects to have 230 million people, more than enough to make it 1000 people for each one of our 226,000+ practicing physicians, and who are mostly concentrated in the industrial and wealthy states that can attract and hold them, and THESE are the states where the President has won a simple majority in the primaries, but when he went to a state that is mostly farming and where there is little or no health care in many of the rural communities, he lost, because THEY are going to vote for ANYBODY who will promise them relief, and there may be enough of them to put Mr. Ronald Reagan and his Social Welfare Reform Program in the White House, barring some Democratic Candidate opening up with the same type of campaign, and if nothing is done to dramatically increase the number of doctors for America, and soon, where do you think we will be 10 or 20 years from now????

Most Sincerely Yours,

Marshall Cline
Marshall Cline.

YOU WILL NEVER BELIEVE THE STRANGLE HOLD MEDICINE HAS ON AMERICA, OR HOW TIGHT THE NEWS MEDIA CAN CLAM UP, OR HOW FAST OUR " PUBLIC SERVANTS " CAN RUN, UNTIL YOU TRY TO GET HELP TO GET SOME OF THAT FAMOUS EQUAL LIBERTY AND JUSTICE FOR ALL, AND ONLY AMERICA ALLOWS SUCH MAIMING AND MURDER BY MALPRACTICE!!!!!!

Marshall Cline

STOP BEING A 2nd CLASS CITIZEN

COME ALIVE AGAIN VOTE IN '76

THE OLD FOLK'S LOBBY No. 12

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OF OUR LIBERTY HAVE BECOME THEIR WAILING WALL!!!

Newsletter or March 1, 1976

Mr. Jimmy Carter,
2000 P Street NW,
Washington, D C 20036.

Dear Mr. Carter:

Since August I have been trying to convince the White House, Congress and the Candidates that THIS is the year the Senior Citizens will be a dominant force in the elections, and without a program to help meet their needs, NO CANDIDATE can be elected to National Office, and those that did not believe are already falling by the wayside, and those that do are getting busy in our behalf, and we are, at last, beginning to get some action.

For 18 months I have been preaching the gospel that there is nothing wrong with Social Security, Medicaid or Medicare that a total elimination of all the graft, corruption and fraud will not correct, but it has been like fighting our Sunday Schools, the Flag and Motherhood to even suggest there is nothing sacred about Medicine, and that doctors are not HOLY men, but BUSINESS men, and in every business there are those who are quick to take every advantage to make a buck, and the T V Doctor Idols and their Fairy-Land Hospitals are really make-believe and only show-biz after all, but America is so dazzled they refuse to see the faults and failings of Medicine in real life, until it happens to them, and then it is too late, and now, at last, little bits and pieces of the whole sorry mess are beginning to surface and be seen on our T V News Programs and in our daily papers and for the millions of the suckers of the system like myself, it is not news at all, but is most welcome, and we hope to see much more in the future.

For those who wonder who is keeping the store on the Potomac, consider Senator Edward Kennedy, the only man in America who only needs to say "YES" to be elected our President, yet in spite of his power in Government and the esteem of the voters, he has yet to get to first base with his National Health Security Bill that would assure every American of proper health care we can afford and end forever the ABSOLUTE MONOPOLY and the LOBBY IN WASHINGTON that controls the health care of every American from the CRADLE TO THE GRAVE, and is now making the first costs of ordinary health care prohibitive for too many of our people. When we walk into a doctor's office today, we no longer find the friendly and trusted institution we once knew, but a tough business operating on a cash-on-the-barrel-head basis, and where there is no service without instant pay, and poverty is no excuse, and the last penny of the grocery money is gladly accepted, and our Social Security Cards that PROMISED so much, are only good for a partial refund sometime in the future, maybe, and if we must go hungry in the meantime, nobody cares, and the difference between darkness and light will aptly describe the difference between the health care those at the top receive at Bethesda, and the health care we at the bottom receive elsewhere, and how many of our \$200.00 a month retired people, who are trying to live in a \$1000.00 a month society, can save the money now needed to pay the first costs of their health care when they can barely exist if they are fortunate enough to enjoy good health in old age.

Doctors today make it ALL. They build clinics where they OWN AND CONTROL every step in medicine from the first office call to the hospital, and they must admit you there. These clinics contain their offices, laboratories, xray suites, diagnostic facilities and the pharmacy. The first office call is \$15.00, and only includes a routine examination, and so is the 2nd, or 3rd. A blood count will be wanted, another \$14.00, and everything else is also extra. Xrays start at about

\$35.00 and the sky is the limit, so it is easy to spend 3 days and \$200.00 BEFORE IT IS DECIDED you need to go to the hospital, and it must be paid for in CASH, UNLESS you have bought THEIR Blue Shield Insurance Policy from THEM, because no other insurance sold in America will pay these first costs and at once, and the pharmacy will fill your prescription, ALSO FOR CASH. Many doctors never WRITE A prescription, they tell you to pick it up at the pharmacy on the way out, and phone the pharmacy after you leave their office, and you can be sure they do NOT do all the procedures THEIR insurance pays for that they do when Medicaid or Medicare is paying the bill.

If hospitalization is needed, the doctor must admit the patient, and retains his complete control as long as you are there, and he is the BOSS, right or wrong, and no other doctor may try to help you, REGARDLESS OF THE CIRCUMSTANCES, unless he has been requested to do so by the ADMITTING doctor, and in spite of you paying all the bills, YOUR CHARTS ARE NEVER YOURS, never to be seen or touched by you, but if you have a reason to pay an attorney \$150.00 and up, he can get you about \$10.00 worth of zerox copies, another nice angle, and all you can do is ask to have them transferred to another doctor if wanted, that is, if you are still alive and able to ask, so when we add it all up, we have a super smooth operation that makes Ma Bell, I B M and Mobil look like Santa Claus, and that's not all. They have a Congress that will fight you every inch of the way if you try to change anything, and if you don't think so, try to find out how many years ago the new Veterans Administration Hospital for Beaumont was first PLANNED, and when it was APPROVED AND FUNDED, and when it will BE BUILT!!!, and who else has a Lobby that was big enough and tough enough to tell America in WARTIME we could NOT have a Medical Academy to train doctors for the armed services, and have made it stick, even today, and they can't kid me, BECAUSE I WAS THERE!!!

In 1942 I was pouring concrete in the War Department's Classified Construction, and during a slack period, being anxious to be back in uniform, and too old to return to the Marines, I enlisted in the U S Army Air Force, and in 1943, while serving at Ellington Field, their grapevine carried the story of the planned new U S A F with it's own Academy to train the flyers, and it was built right on the schedule with no trouble whatever, and is the pride of the Nation. Later on, the War Department needed me more than the Army needed a cook, so I was sent back to them to pour more concrete, and their grapevine carries the story of the planned Medical Academy to train doctors for the services, and because we had the labor, equipment, the time and material AND THE LOCATION, we were sure we would be in it but it never happened. I doubt if you can find any record of this business, and some will claim it was only a rumor, but try to find another RUMOR that still occupies a choice location, in the middle of the complex, of one of the most respected Medical Schools in America, and was later enacted into law disguised as a new U S P H S Hospital by the Congress, and stopped by the simple process of failing to appropriate the money when it was leaked there was a U S P H S hospital already in the area, which shows our Congress can butter their bread on both sides, and keep everybody happy.

I have always believed it was a factor in selling the Medical Profession those GOLD MINES we now call Medicaid and Medicare, and was tied into the deal so it would be quickly forgotten when Medicare was on the books and working, and so it was, except for the people who were involved and have lived this long, but the location is still there, vacant, and waiting. For those who will doubt this story, I will gladly display my U S Army Dog Tag #18189285 for 1942, and the I D Badge with my picture, that I proudly wore in 1943. I sincerely thank you for your attention, and I will welcome any comment you may wish to make.

Most Sincerely Yours,


Marshall Cline.

chips
you handle
DEM

6/14/76

To Whom:

George Fernau ((r) 314-837-7053, (o) 741-5690) called me today to ask about recognition of a group of handicapped who are organizing into a political pressure group. At this point they are nascent. He ~~He also~~ would be glad to work with them.

He also wanted to know whether his singing group could perform ~~at~~ at the Inauguration.

Please contact him about both of these items & drop me a line about what comes out of it.

Thanks
Jack Carter

LOUIS

Lionel Lewis
April Song Apt. 116
1333 East Hallandale Beach Blvd.,
Hallandale, Florida 33009

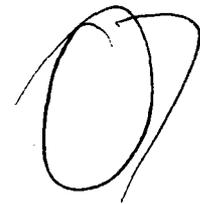
Hon. Jimmy Carter
The Jimmy Carter Presidential Campaign Headquarter
P. O. Box 1976
Atlanta, Georgia 30301

Dear Mr. Carter.

I know that you want to be president of our nation, but there are some question, that, I would like to ask you, before I can judge, whether you and other candidates for the president of the United States which problems, which you have on the handicapped employment side..The job programs, never have been solve. Since every president never have able to to help the handicapped at all. The only problem is job in the state of Florida. Do you have the same problem in your state of Georgia in the handicapped field? I don't know who I will support if nominate by the convention, both republican and democate. I would like to know what they would do before we, the handicapped people, vote and support their nominate. I would like very much to have your program, whatever you have, on the handicpped in Georgia. If I decide support you for the 1976 election, I will not be able to support the republican plateform commitee if they cannot give any job for the handicapped in the national interest, but I would like to get some idea on how the handicapped stand on, before they can vote on. If they are something wrong in democate plateform, therefore we cannot vote on either the democate or the pateform.

Sincerely Yours,

Lionel Lewis



THE WHITE HOUSE

WASHINGTON

September 3, 1976

Dear Mrs. Taylor,

Thank you for your letter informing me further of your son's condition and of your efforts to focus attention on the relationship of spinal cord regeneration research to an eventual cure for paraplegia.

Recent developments indicate that your initiatives and those of other citizens and organizations with an interest in paraplegia have been highly effective. As mentioned in your letter, the Veterans' Administration, the Congress, the National Institute of Neurological and Communicative Disorders and Stroke, and leading neuroscientists at medical centers throughout the country recognize paraplegia as a national health problem and have expressed their determination to press toward its solution. Already scientists are working singly and in concert to fill in crucial gaps in knowledge about regeneration in the central nervous system. This basic information is essential before any all out attack on the problem of paraplegia can get under way. As pointed out in your letter, the fundamental knowledge needed to develop the technology for putting a man on the moon was already at hand before the landings were undertaken.

Please know that the President is well aware of the great need for research and advancement in the field of central nervous system regeneration as well as the extraordinary financial burdens that such injuries place on both victims and their families.

In pledging his support for this research, the President stated on April 10, 1976; "I can assure you that whatever funds the VA or the National Institute of Health or any other agency of the Federal Government can come up with a program, there will be no hesitancy as far as I am concerned in recommending the funds they request."

Being a mother myself, I can well understand the anguish you are experiencing during this period of waiting. I can only offer you my faith and confidence that everything is being done to speed up the progress of this much needed research.

-2-

The President and I wish to assure you, your husband, Mike and others like you, that you are in our thoughts, and we pray for the day when Americans no longer have to suffer as a result of paraplegia.

With our prayers and best wishes,

Sincerely,

Betty Ford

Mrs. Barbara Taylor
15515 52 Avenue West
Edmonds, Washington 98020

1-A

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LYLE G TAYLOR
15515 52 AVE WEST
EDMONDS WA 98020

THIS MAILGRAM IS A CONFIRMATION COPY OF THE FOLLOWING MESSAGE:

2067430887 MGM TDMT EDMONDS WA 219 08-31 0016A EST
ZIP
MRS BETTY FORD
WHITE HOUSE
WASHINGTON DC 20500
SUBJECT: CENTRAL NERVOUS SYSTEM REGENERATION RESEARCH FUNDING

ON JUNE 19 1976 I SENT YOU A 34 PAGE DOCUMENT WHICH PERTAINED TO THE SUBJECT. THIS WAS IN RESPONSE TO YOUR LETTER TO ME DATED JUNE 7 1976 WHICH WAS IN ANSWER TO MY MAILGRAM TO YOU DATED MAY 27 1976. ON JULY 21 1976 MY HUSBAND CALLED MRS ELIABETH M O'NEILL, YOUR DIRECTOR OF CORRESPONDENCE, AND SHE RETURNED HIS CALL ON JULY 22 1976 WHEN SHE STATED THAT SHE WOULD HAVE AN ANSWER TO MY JUNE 19 1976 LETTER AND SUPPORTING DATA WITHIN 24 HOURS, BUT I HAVEN'T RECEIVED THE ANSWER YET

I KNOW YOU HAVE BEEN VERY BUSY, BUT WONDER IF YOU HAVE MADE ANY HEADWAY ON CONVINCING YOUR HUSBAND TO ACCEPT THE HEW BILL THAT IS NOW BEING FINALIZED IN CONGRESS. IF MR FORD WON'T ACCEPT THE BILL, COULDN'T HE CALL FOR A SEPARATE BILL FOR THIS CRITICAL PROBLEM? IN THE HEW BILL IS 9.5 MILLION EXTRA FUNDING FOR NERVE CELL REGENERATION RESEARCH. MRS FORD, THAT MONEY IS DESPERATELY NEEDED NOW, JUST THE SAME WAY THAT THE MILLION PLUS THAT THE AMERICAN LEGION RAISE FOR CANCER RESEARCH

CAN'T YOU PLEASE HELP THE THOUSANDS OF CURRENTLY PARALYZED PEOPLE AND THE ONES YET TO BE WITH SOME POSITIVE ACTION NOW? VERY SINCERELY

BARBARA TAYLOR
15515 52 AVE WEST
EDMONDS WA 98020
TELEPHONE 2067430887

00:16 EST

MGMCOMP MGM

1-B

June 19, 1976

Mrs. Betty Ford
White House
Washington, D.C. 20515

Dear Mrs. Ford,

I am thrilled to see your interest in the subject of "Growth and Regeneration of the Central Nervous System (CNS)" that I briefly discussed in my mailgram to you on May 27, 1976.

I would like to draw your attention to what my husband, our son Mike and I have researched out on the subject of CNS growth and regeneration.

On behalf of the millions of people in the U.S. alone, and their families that would benefit from finding answers that outstanding neuroscientists in the U.S. and throughout the world definitely believe possible, I ask for your indulgence of more time, interest and action as this is a fairly long story.

As you will recall in my mailgram, (Exhibit #1), our son Mike broke his neck in a motorcycle accident on March 15, 1974 in Everett, Washington. He has now recovered to the point where he has minimal use of both arms, but does not control either wrist nor hands; the rest of his body is paralyzed. My husband Lyle, and I have taken total care of Mike since he was discharged from the University of Washington Hospital, August 30, 1974. When Mike became able we started looking for answers to solve his problems by traveling as we had called and written to everyone we knew.

The doctors at the U of W (1 of the 4 best in the U.S.) told us repeatedly that Mike had all of the return that he would ever get; that we must accept this condition and make the best of what he had; try to keep him well and away from all the terrible problems associated with paralyzed human bodies etc.

Frankly, we could not accept the doctors answers then and we don't accept them now. Our research has resulted in finding that there are dedicated neuroscientists here in the U.S. and various places in the world that have worked long and hard on this subject. They have found the decision that the Egyptians made 4000 years ago was wrong and the myth that we have lived under since that CNS will not regenerate and grow thus is false.

We have looked for answers by spending a month in Europe last summer and our travels have taken us up and down and across this great land of ours, many times, spending thousands of Mike's insurance settlement dollars as he is determined that he is going to walk again, and so are we.

In October, 1975, we contacted the Leonard Frank family in Portland, Oregon, due to newspaper articles we had been sent by friends and relatives. We found that the Franks had gone to Russia for emzyne treatments as they were unable to get them in the U.S. for Roger's paralysis and we were just one of hundreds of concerned families that had contacted them about possible aid for a loved one. (See Exhibit #2--one of many articles appearing throughout the U.S. and world as Russia broke the news to the world, including Russia Life, Feb., 1976. At that point in our continuing research and travels we became closely associated with the Franks as both families felt the search for answers could be expedited if we also enlisted the aid of the hundreds of families who continue to write and call the Franks and ourselves. We have now resorted to periodic newsletters to these people located in all of the 50 states and around the world to keep them advised and to maintain hope, to keep them going, one day at a time. (We have been told hundreds of times that we are the only people that these people have found that have any knowledge at all about the research efforts and thus give them a tiny ray of hope in a world filled of pure hell psychologically. We fully understand this as my husband and I try to support our other two (2) children, keep Mike's spirits up and keep our thirty (30) year marriage together. (See Exhibit #3 as one example of a woman's plea).

So what did we find that is so exciting you say?

First, we found that during World War II, Dr. Windle (noted U.S. nueroscientist) was involved with research to help solve a new problem we had, ie, people who had broken their necks died until World War II when doctors found ways to keep them alive. The funding effort was stopped at the end of World War II. However, Dr. William F. Windle was not one to quit, so he renewed some interest in the fact that CNS regeneration was possible through one method he found of injecting an emzyne type material into his test animals right after he had paralyzed them with a blow to their spinal cord. However, the resistance was high among his colleagues and large amount of funds were not readily available in the early 1950's to continue. Dr. Windle and a few others persisted until a conference was held at National Institutes of Health (NIH) of which he is a past Assistant Director. The proceedings and Dr. Windle's findings were published to the nueroscientific community throughout the world. By 1970, renewed interest brought a group of highly trained nueroscientists together in Palm Beach, Florida and a lot of the doubters came away believers--- "the human body could and would create regeneration in the CNS, but in the case of spinal cord injury, the body formed scar tissue faster than the spinal cord could regenerate thus paralysis of the body below the injury". (Consequently, more scientists started looking for additional ways to offset the growth of scar tissue).

(Please see Exhibit #4) note that 1,969 Scientific Publications Have been written relating to Regenerative Phenomena of the Central Nervous System--as noted therein) and (Please then refer to Exhibit #5--some very interesting facts are outlined by a very prestigious group of dedicated people that collectively and individually can verify to you in person what I am telling you in this letter as I outlined to you in Exhibit #1). Next, I would like to call your attention to Exhibit #9--a special message dated 6-2-76 to your husband, calling to him to hear the desperate pleas made for the millions of people.

To continue the brief outline of events leading up to my mailgram to you, we found that enough interest existed in the scientific community by 1974 that Dr. Windle was asked to go to Russia as a representative of the National Institutes of Health to verify the many reports coming from Russia that they were using emzyne to combat paralysis and reportedly were having excellent results. Dr. Windle found that when he got to Russia and talked to their top scientists, they had translated Dr. Windle's publications made earlier, tried the methods on animals in their laboratories and found that when emzyne treatment was made immediately after injury (acute stage), a large percentage of the test subjects were never paralyzed!

Dr. Windle came back with this news to NIH and by this time Leonard Frank was in contact with him. Thus the Frank family's trip to Russia, February 1975, for emzyne treatment that he couldn't get in the U.S., and yet our scientists and our tax money made the scientific breakthroughs!!

The many stories that had been written about the Frank's in Russia created many questions by anxious people seeking help that were directed to Dr. Donald Tower, Director, National Institute of Nuerological and Communicative Disorders and Stroke (NINCDS) Bethesda, Md. Under this pressure Dr. Tower responded by inviting the Russian doctors to the U.S. for an exchange of information. (See Exhibit #6--Dr. Tower's letter to Senator Hart and see Exhibit #7). Our son was examined by the same Russian doctors in the Russian Embassy, Washington, D.C. and was told exactly the same thing as Greg Bedan. As you will note in Exhibit #7, Dr. Matinian is the doctor that has used the emzyne "trypsin" with great success he tells us and he used it in the acute stage--paramedics give it on the accident site--and this is to people like you and me, our husbands, and our children. Dr. Windle has run tests on animals since his trip to Russia and verified the Russian statements as fact.

While we were in Washington, D.C. last month, we were able to meet with Senator Warren E. Magnuson, and Senator Henry M. Jackson, and discuss at great length this subject matter. As you might know, both of these men have been involved in health care programs for years and we found them to be up to date and ready to go into action when they found that the U.S. and world

Scientific communities were waiting for more funding. My husband and Mike also had a long conference with Dr. Tower on May 20, 1976 about the need for more monies as NINCDS is not able to fund even one-third (1/3) of the requests that are approved and sitting on his desk.

As a result of the meetings held in Washington, D.C., the Senate Appropriations Committee this week has marked-up the Fiscal 1977 H.E.W. Bill and added \$10 million to go to NINCDS for CNS research. In conferences between my husband and Dr. Richard Sidman, (See Exhibit \$5 and #8), and Dr. Carmine Clemente, they have told him that each one of the institutes they represent could easily handle grants in excess of \$1 million right now and have space and manpower available immediately to proceed with research that could very possibly lead to help for people yet to be afflicted with a nuerological disorder and those that have already been hurt or suffer from the effects of stroke etc. and these are just two (2) of the facilities ready to move out.

Mrs. Ford, I realize that this is a long letter with many references, but it is a major national and world problem, not only in uncalcuable human suffering, but in the economic phase also. For instance, the V.A. has recently determined that it costs \$900,000 to pay for the care alone for Mike the rest of his life. He receives \$156.00 a month from Social Security and in September will be elegible for Medicare. If he gets sick with one of the many potential problems that paralyzed people have facing them, Medicare and his monthly pension will not cover his medical costs, so who takes care of him when my husband nor I can? The taxpayers in an institution somewhere I imagine---right? So what are we saying--it looks like the only way we can help offset the financial burden that is now upon the tax paying citizen and will bear ever so much heavier in 1977, 1978,---- and on is to take action before we bankrupt Social Security.

Dr. Tower called my husband last week to tell him that NINCDS has decided to run extensive tests with trypsin as Dr. Matinian has done. Mrs. Ford, we need these scientific aids to be used on our own people--now--not twenty (20) years from now. My husband spent thirteen (13) years of his life working as an engineer in research in the missile and space programs and he saw many totally impossible things changed to become functional. One of his jobs was Director of Quality Assurance and Engineering, Spacelabs, Inc., Chatsworth, California and he played a role in helping design, develop and manufacture the bio-medical monitoring equipment that monitored all of the physiological functions of all the astronauts in all flights of Mercury, Gemini,

Apollo and the Russian/American docking flights. Concepts were found through research that turned many impossibles into highly sophisticated percision equipment. We feel that through a real concentrated effort, the millions of people in the U.S. today can be helped as the nueroscientists are saying that we are at the threshold of a fantastic new era and all it takes is for someone to say go! (See Exhibit #10). Your husband has told Kelly Forehand, Canyon, Texas, a C-4 Quadriplegic like Mike, Roger Frank in the White House and Sherry Seitsinger in Portland, Oregon that he is 100% for any program that the V.A. or N.I.H. had that would find answers for them to get out of their wheel-chairs. (Please see Exhibits #II-Amarillo Daily News dated April 12, 1976 and #I, notes taken from Mr. Ford's Question and Answer file).

Now that there is a program at NINCDS, many nueroscientists are anxious to explore the unknown and Congress has made its move, would you please become personally involved in this matter, call some of these people to verify what I say is true and talk to your husband immediatly about this most desperate vital national issue?

As I have tried to outline this huge subject as quickly as possible, I have also tried to be very candid with you as I did in the mailgram. I want to assure you that this subject will not be dismissed by a "ho-hum" attitude because if you do not care as the "First Lady" or, if your husband does not care about the average John Doe and his problems when he can help, then we will take the necessary steps to make sure that many people know that the Ford Administration's policy does not include the cares and needs of the people. As you can see our files contain many pieces of evidence that says that we as untrained medical people are not just well-wishers. The Frank family and ourselves have been trying to get this subject before your husband for his concentrated review since last fall and some of the people you might care to check this with are:

Mr. Richard Cheney
White House-Assistant to Mr. Ford

Sara Massengale
White House-Domestic Council

Barbara Wise
Ford for President-Assistant
Executive Director to Rogers Morton

Why can't your husband call for Congress to put a special bill for \$10-\$15-\$20-million for CNS research now, and separate it away from the complex H.E.W. bill which it is currently a part of and this will get the show on the road? He had stated three (3)

times now that he is 100% behind the program, so now for the mothers across this great land during our bicentennial year can you slow your husband down long enough to convince him that this is such a vital issue that the country and your family needs his action? I do notice that he does have time to send \$25 million to Italy on a moments notice for their earthquake and declare parts of Idaho a national disaster area to help them. Have you ever thought about how many homes fall apart every day across our nation because we have not taken steps to preclude what is happening now?

We have talked to many paralyzed veterans across this nation and they are mighty bitter because the V.A. has been telling them that they have a research program for spinal cord injury to get them help and then the V.A. was forced to admit that they haven't had a program and are only trying to budget one now. Is it any wonder that they haven't received many inquires for grants? And then when you have a "Nam Vet" who is paralyzed and has been lied to----Mrs. Ford he is mad!

In closing I want to thank you for your time, thought and effort and I hope and pray that you will find the time to really research this subject and then sell it to your husband because I believe that there is sufficient evidence contained herein to do the job.

I feel that this is a most shameful condition for our country to allow to exist when we supposedly lead the world in many things and we send Mr. Kissenger all over the world to solve problems and yet we can't correct tremendous problems like this!

We hope President Ford's commitment to those three (3) young people are real solid as he made them to "prisoners in wheelchairs" because people years ago did not hear what people like Dr. Windle said. (See Exhibit #II). We are counting on you to take us away from our "Days of Shame" and give people new hope that something is being done for them.

Sincerely yours,

Barbara Taylor

Barbara Taylor
15515 52nd Ave. W
Edmonds, Wn. 98020
206-743-0887

P.S. May I hear from you personally in the next few days? We would like to know what your husband and you plan to do about this problem. Conservative estimators point out that a cure for paraplegics would exceed a savings of over \$2 billion per year in the United States alone.

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EXHIBIT #1

LYLE G TAYLOR
15515 52 AVE WEST
EDMONDS WA 98020

THIS MAILGRAM IS A CONFIRMATION COPY OF THE FOLLOWING MESSAGE:

2067430887 MOM TDMT EDMONDS WA 505 05-26 1045P PDT
ZIP

MRS BETTY FORD
WHITE HOUSE
WASHINGTON DC 20500

FROM ONE MOTHER TO ANOTHER MOTHER THAT IS DEEPLY CONCERNED ABOUT THE SAFETY AND WELFARE OF HER CHILDREN AS YOU ARE ABOUT THE HAZARDS YOUR SON STEVE IS EXPOSING HIMSELF TO WHEN HE RIDES IN RODEOS. I WOULD LIKE TO ASK YOU WHERE YOU WOULD GO FOR HELP IF HE BROKE HIS NECK AND WAS PARALYZED FROM THE NECK DOWN AS MY 20-YEAR OLD SON IS? THE DOCTORS WOULD TELL YOU TO REHABILITATE HIM TO LIFE THE BEST YOU CAN, AS THE RUSSIAN NEUROSCIENTIST TOLD US IN YOUR CITY LAST WEEK.

MRS FORD, YOU UNDERSTAND PAIN, SUFFERING AND TRAGEDY AS YOU HAVE HAD CANCER, BUT AT LEAST YOU CAN WALK AND TRAVEL AND CALL PEOPLE ON YOUR NEW C.B. BY YOURSELF. IF TAKES MY HUSBAND AND MYSELF WHO TRAVEL WITH MIKE, WITH SPECIAL CARE AND ARRANGEMENTS ALL THE TIME.

WHAT WOULD YOU DO IF ONE OF YOUR CHILDREN WAS PARALYZED FOR THE REST OF HIS LIFE AND EVERY DAY IT TEARS YOUR GUTS OUT AND CONTINUES TO ERODE THE FOUNDATION OF YOUR MARRIAGE.

MY HUSBAND AND I PERSONALLY TAKE CARE OF OUR SON MIKE, TWENTYFOUR HOURS A DAY, SEVEN DAYS A WEEK, WHO IS A PRISONER IN A WHEELCHAIR BECAUSE WE CANNOT GET YOUR HUSBAND'S ATTENTION TO THIS PROBLEM. YOUR HUSBAND HAS BEEN PERSONALLY CONFRONTED BY THREE YOUNG PEOPLE IN WHEELCHAIRS RECENTLY, IE KELLY FOREHAND, CANYON TX APRIL 10 1976, ROGER FRANK THE WHITE HOUSE OVAL ROOM MAY 21 1976 AND A YOUNG LADY IN PORTLAND OREGON MAY 22 1976. THE ANSWERS WE GET BACK FROM THE PRESIDENT WHEN ASKED ABOUT THE NEED FOR SPINAL CHORD REGENERATION RESEARCH MONIES IS THAT THE VETERANS ADMINISTRATION HAS A PROGRAM. MRS FORD, HE IS MISINFORMED -- ON MAY 20 1976 DURING CONGRESSMAN BILL FRANZEL'S LUNCHEON ON THIS SUBJECT, DR WARREN HUBER, DIRECTOR, NEUROLOGY SERVICE, VETERANS ADMINISTRATION, TOLD US THAT THE V.A. HAD NOT SPENT ONE DOLLAR ON SPINAL CHORD REGENERATION RESEARCH THUS FAR.

WE HAVE BEEN TOLD THAT THE SENATE WILL REVIEW THE BILL FOR THIS ON JUNE 2, 1976 AND WILL ADD FUNDS BUT ARE AFRAID YOUR HUSBAND WILL VETO.

8



western union Mailgram®



MRS FORD, WE ARE SINCERE, HONEST AVERAGE CITIZENS THAT ARE DEDICATED TO FINDING ANSWERS THAT NEUROSCIENTISTS TELL US ARE NOW POSSIBLE TO HELP 200,000 PARAPLEGICS, 2 MILLION STROKE VICTIMS, MULTIPLE SCLEROSIS 1/2 MILLION, HEAD INJURY 3 MILLION, MENTAL RETARDATION 6 MILLION TO NAME A FEW.

WE HAVE TRIED TO REACH YOUR HUSBAND EVERY WAY POSSIBLE AND NOW WE TURN TO YOU. IF I DON'T HEAR FROM YOU IN PERSON REGARDING THIS PROBLEM BY JUNE 2 1976 WE WILL RESORT TO THE FOLLOWING:

"DAYS OF SHAME WHEELCHAIR MARCHES" THROUGHOUT THE COUNTRY -- GUARANTEED.

YOUR HUSBAND WON'T ANSWER OUR LETTERS AND MAILGRAMS, BUT HAS SOMEONE ELSE DO SO, AND WHEN WE SPEND 20 BILLION DOLLARS A YEAR IN THE US TO TAKE CARE OF PEOPLE WITH NEUROLOGICAL DISORDERS, FIRST MAMA -- WE HAVE A STORY TO TELL AND WE WILL TELL IT WITH DOCUMENTED EVIDENCE. THANK YOU FOR YOUR TIME AND ACTION.

SINCERELY,

BARBARA TAYLOR
15515 52 AVE WEST
EDMONDS WA 98020
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Las Vegas
REVIEW-JOURNAL

NEVADA'S LARGEST AND MOST COMPLETE NEWSPAPER

LAS VEGAS, NEVADA, MONDAY, MAY 3, 1976

VOL. 68 NO. 28

PHONE 385-4241

15 CENTS

40 PAGES

Steve Ford 'busts' bronc during riding seminar

SPRING CREEK (AP) — Casey Tibbs didn't try very hard to talk Steven Ford out of riding bucking broncs in this Eastern Nevada town.

The former nine-time world champion bronc rider, now an instructor, said at the start of the weekend he would try to change the President's son's mind about getting aboard. He called it "risky."

But the 19-year-old Ford took his turn and came away with some good rides after a quick fall the first time out of the chute.

"I think I learned more at this one (riding seminar) than the two before," Ford told reporters Sunday just prior to one of his successful rides.

Tibbs, Ford's mentor, hurried to congratulate the college student and would-be rancher at the end of one particularly tumultuous ride, telling him:

"You're looking better every time, you're starting to see what I mean, aren't you." Ford nodded that he was.

The two were in town for a benefit bronc riding clinic attended by about 40 young cowboys. Tibbs provided the expertise, while Ford provided additional name recognition and out of it came some learning and about \$1,000 for an Elko school for the retarded.

While his father was watching the Texas primary during the weekend, young Ford was thinking about anything but politics.

Between work on a mechanical bucking bronc, work on the real thing and helping Tibbs with the students, not to mention signing frequent autographs, Ford was busy.

Today he is back at Cal Poly Pomona, where he is learning how to raise cattle. When he isn't in school he works on a quarter horse ranch.

Some of the cowboys came to watch Tibbs, the acknowledged master of bronc riding. They wanted to learn how to improve and win more

money on the rodeo circuit, the way Casey did for so many years. Not Ford, though.

He came to learn more about animals for the future. He is, as they say, "into ranching."

Outfitted in jeans, a Western shirt, a cowboy hat, a wide belt and boots, frequently a cigarette dangling rakishly from his mouth, Ford looks the part of a 19-year-old cowboy.

Tibbs called the rangy Ford a natural athlete and cowboy.

"I had to do good, whether I wanted to or not, there was no place else for me to go when I was his age," Tibbs said. "He wants to do this and doesn't have to. I think that is better for learning."

Ford said his parents do not object to his rodeo activities.

"I suppose you could say they are concerned about me riding 1,200 pound animals," he said, "but they let me make my own decisions about what I'm doing."

MIKE TAYLOR
STATES THAT —

"I ALWAYS THOUGHT
THE TERRIBLE

ACCIDENTS HAPPENED TO THE OTHER
GUY"

THE WHITE HOUSE

WASHINGTON

June 7, 1976

Dear Mrs. Taylor,

Mrs. Ford has asked me to thank you for writing telling her about your son's medical situation. She was deeply concerned to learn of the difficulties your family has been encountering.

You will be interested to know that Dr. Warren Huber has discussed the fact that much which has been tried in spinal cord regeneration and other spinal cord research has failed. As a result, the interest of medical researchers in this area has been low, and the V.A. has not received numerous research proposals. Despite this problem, however, V.A. is continuing to stress spinal cord research.

For your information, I am enclosing the most recent figures compiled on this topic as well as an excerpt of a press session which took place at West Texas University. I hope that your questions have been answered.

Mrs. Ford did want you to know of her encouragement and hopes that the coming days will bring happiness for you and your family and that the President joins her in extending their warm good wishes.

Sincerely,

Elizabeth O'Neill

Mrs. Elizabeth M. O'Neill
Director of Correspondence
for Mrs. Ford

Mrs. Barbara Taylor
15515 52 Avenue West
Edmonds, Washington 98020

VA SPINAL CORD INJURY RESEARCH REPORTED TO U.S. SENATE: In compliance with a request from the U.S. Senate, the general scope of the research program in spinal cord injury, as it was assessed in December, 1975, along with estimated costs was outlined in the table below and reflects the approximate figure for fiscal year 1976.

	<u>Dollar Amts. (1 yr.)</u>
1. <u>Spinal Cord Regeneration</u> -----	\$ 101,086.00
This includes the subheadings of Plasticity in the Central Nervous System, Nerve Regeneration, and Synaptogenesis (9 projects).	
2. <u>Spinal Cord Protection After Injury</u> -----	239,000.00
Major programs have been initiated at VA Hospitals in Miami, Hines, Cleveland and West Roxbury.	
3. <u>Medical Problems of the Paralyzed</u> -----	412,000.00
Alleviation of spasticity, Neuro-electric stimulation, Genito-Urinary function, Psycho-Social Rehabilitation. (Approximately 72 projects).	
4. <u>Rehabilitative Engineering for the Paralyzed</u> ----	1,817,343.00
Devices to assist or replace limb functions, Mobility aids, Environmental controls, Clinical application and evaluation (constitutes 83% of this category).	

It is hoped that the figure can be increased by an additional \$800,000 in FY 1977. Because of the importance of this field, commitments have already begun to increase and it is hoped that they will do so particularly in the areas of spinal cord regeneration.

In collaboration with the National Institutes of Health, the VA is following the Russian approach to this problem with interest. At the present time, there is no clear-cut evidence of superiority of their approaches over the VA's, particularly in the human. Further interchange with them is anticipated in May when two of their scientists will be visiting this country.

RUSSELL D. BOWMAN (15 C)
 Chief, Scientific Communications Unit
 Office of the ACMD for R&D, DM&S

EXHIBIT #1

Q & A File

Thank you.

—QUESTION: Mr. President, I am sure that you are aware that scientists in our country are working toward a cure for paralysis in spinal cord injuries, and these men must have money for research. I would like to ask you if you plan to support these men in every way so that thousands like me can get out of the wheelchairs?

—THE PRESIDENT: I know that the Veterans Administration asked for additional funding and help and assistance to continue or to expand research in the areas in which you have indicated. It is my best recollection that we recommended an additional amount of money for the expansion of such research to try and find some answers, not only answers in the United States but to work with other scientists around the world.

I was told at the time we considered the budget that there were some excellent programs in other countries, including the Soviet Union, in this particular field. So, I can assure you that whatever funds the VA or the National Institute of Health or any other agency of the Federal Government can come up with a program, there will be no hesitancy as far as I am concerned, in recommending the funds they request.

After Soviet surgery (EXHIBIT # 2) Portlander progressing

By ANN SULLIVAN
of The Oregonian staff

Greater detail on the treatment of Roger Frank, Portlander who went to Russia seeking aid for a spinal cord injury, has been released by Sen. Mark O. Hatfield.

Hatfield, in a letter to Caspar Weinberger, secretary of Health, Education and Welfare, said Soviet and American physicians cautioned against premature optimism. But, he said, interest in the case has been expressed by many, and he wanted to relay the most recent information.

He also asked Weinberger to encourage exchange of information, research and experience "so that physicians and patients in both countries and elsewhere in the world will have the fullest possible benefits of these efforts."

Hatfield asked if additional legislative authority or funding was needed to assure cooperation.

Letters from Roger's father, Leonard E. Frank, said the 19-year-old has been under treatment for spinal cord injuries at the Polenov Neurosurgical Research Institute in Leningrad since Feb. 14 as a "guest-patient"

of the Soviet government. He is believed to be the first U.S. citizen to undergo treatment there for an injury not suffered in the U.S.S.R.

"Roger fractured two vertebrae, C-6 and C-7, in a swimming pool accident in Portland Aug. 18, 1974, with the main damage occurring in the C-6 region," the father said. "An operation to stabilize the fractures was performed at Kaiser Hospital in Portland 10 days after the accident.

"Roger arrived at Polenov Institute with both legs paralyzed and very limited hand functions. March 25, he was operated on at Polenov for the purpose of removing bone fragments which the institute had discovered were pressing on the spinal cord. The operation was performed successfully and Roger is experiencing increased sensory responses in his legs and trunk, as well as finger and thumb movement, previously minimal. He is continuing to receive certain other therapy, oxygen while in a compression chamber and also a unique form of physical therapy.

"Other types of treatment are under consideration, one

believed to involve the use of certain enzymes which may aid in nerve cell function regeneration."

Further progress was reported by the father in a second letter:

"I know you will be as delighted as we are by the following developments," he wrote Hatfield. "Today, Roger used a soft-tip pen and printed his first writing since his accident last August, a very legible letter to his girlfriend, Paula Schreiber, at the University of Oregon. Much to his relief he will no longer have to dictate such letters to his mother or me.

"Following the operation here March 25, Roger began to move his thumbs for the first time and his fingers increasingly. Polenov doctors assure us all that he will be able to write normally, use a typewriter and have all or most all normal uses of his hands.

"Several days ago, Roger was the star performer before about 200 doctors who assembled in the Polenov auditorium from all over the Soviet Union. He managed to take about 40 steps in a walking-aid apparatus, using leg braces.

How CAN WE TELL OTHER
COUNTRIES WHAT TO DO WHEN
WE DON'T LEAD?

18 December 1975

Dr. Donald Tower
National Institute of Neurology & Stroke
Dept. of Health, Education & Welfare
Bethesda, MD 20014

Dear Dr. Tower:

Recently I read in "Experimental Neurology" about an enzyme called hyaluronidase used in the regeneration of nerves of the spinal cord. I also spoke with a gentleman who had taken his son to Russia for an operation as a result of a spinal cord injury and the Russians prescribed this enzyme. Can you send literature or any information on this important discovery?

I am very interested in this because of the lack of knowledge in the United States in this area. I have been told that the United States knows more about the spinal cord than they let the public or the victims of this terrible injury know. Why? Why is more money not spent on research in this area? When you think of all the money spent on cancer research and other diseases, why is more not spent on the study of regeneration of nerves in the spinal cord?

It's true this injury is not terminal, but when you think of all the people (mainly young people) that are injured this way every year, it's really a pity. When you take a perfectly healthy adult, 27 years old, one day they are so normal and active in every way, but that night they are involved in a car accident and when they come to they have no control over their bowels, their bladder; have no feeling from the chest down (just to mention a few of the tragic things that go along with this injury) and they are told by every doctor that they will never walk again, but to be thankful for what they have left; with all our technology and know-how, that there is nothing more a doctor can do for you and that that is the way you will be left for the rest of your life. I, for one, cannot accept this answer.

Any information you could send me on the advances in this field would be so appreciated. I, for one, think "false hope" is better than no hope at all. Please send any information available. Thank you.

Sincerely,

Susan L. Tate

/slt

NATIONAL PARAPLEGIA FOUNDATION BASIC LIBRARY OF PARAPLEGIA PUBLICATIONS

January, 1976

This is the first substantial revision of our BLPP in many years. As usual, our goal is a representative selection of available literature and audiovisual materials rather than comprehensiveness. To the best of our knowledge the materials listed are available at the named source and for the price indicated. Prices are always subject to change and such changes are not always known to us. We have tried to list materials that are in adequate supply and, conversely we have avoided listing anything known to be out of print or extremely limited in supply.

As regards quality, we make no guarantees except that in our judgement, the listings are "respectable" either from personal knowledge or perceived reliability of the publisher. We are aware of certain weaknesses in this library particularly in "handbooks" specifically for paraplegics and quadriplegics. We hope to eventually remedy this gap by producing or finding something appropriate.

Undoubtedly there are other gaps. As we become aware of new and appropriate entries, these will be printed in Paraplegia Life in such a fashion that they can be cut out and added to the original BLPP. Similarly, current listings will be dropped when they are no longer available, pertinent, or unsatisfactory for any reason.

We hope you will remove the BLPP from your Paraplegia Life and use it to good advantage. But whatever your reaction, we would appreciate your comments. We need your criticism, your wisdom, and your suggestions so that the BLPP can be a constantly improving tool. JS

Publications available from NPF National Office

- **CONTINUING EDUCATION IN THE TREATMENT OF SPINAL CORD INJURIES - II** — proceedings of 1972 conference, published by National Paraplegia Foundation. Reports from six DHEW supported SCI clinical research centers; reactions to those presentations from a variety of disciplines; basic research; epidemiology; rehabilitation; reports from federal DHEW officials; and SCI sexuality. 101 pages; available from source no. 1; \$2.00 each for handling and postage.
- **CONTINUING EDUCATION IN THE TREATMENT OF SPINAL CORD INJURIES - III** — proceedings of the 1973 conference, published by the National Paraplegia Foundation. Continuation of reports in latest developments of medical treatment and basic research with additions in prevention, trauma systems, nursing and other allied health specialties, half way housing, case management, and consumer reaction. 201 pages; available from source no. 1; \$2.00 each for postage and handling.
- **CONTINUING EDUCATION IN THE TREATMENT OF SPINAL CORD INJURIES IV** — proceedings of 1974 conference, published by National Paraplegia Foundation. Categories include: Spinal Cord Regeneration; Spinal Cord Injury Research; Advances in Clinical Management; Spinal Cord Centers Report on Progress; Pediatric Spinal Cord Injury Perspectives of Opportunity; and Spinal Cord Injury and Developmental Tasks of Adolescence and Early Adulthood. 218 pages; available from source no. 1; \$2.00 for handling and postage.
- **CONTINUING EDUCATION IN TREATMENT OF SPINAL CORD INJURIES - V** — proceedings of 1975 conference, published by National Paraplegia Foundation. Continuation of new developments with additions in skin care, urology, orthotics, VA Medicine, health insurance, and special seminar on nursing. 192 pages; available from source no. 1; \$2.00 for handling and postage.
- **COST-EFFECTIVENESS OF SPINAL CORD INJURY CENTER TREATMENT** by David R. Matlack, S.B., published by National Paraplegia Foundation (1976).
A thesis written (1974) in partial fulfillment of the requirement for an MBA in Health Care Administration. Chapters include: Treatment of Spinal Cord Injury; Cost Analysis in the Health Field; Cost Comparison Model for Spinal Cord Injury Treatment Methods; Epidemiologic and Demographic Data; Costs and Cost Comparisons; Conclusion; and Bibliography. 11 tables, 5 figures, and 48 pages. Excellent documentation for the effectiveness of good SCI treatment. Available from source no. 1; \$5.00 per copy.

- **HOW TO GET HELP IF YOU ARE PARALYZED** — first edition by Jan Little, revised edition (1975) by Richard J. McCauley, Virginia R. Allen, and Diana L. Reed, published by National Paraplegia Foundation. An introduction to paraplegia and quadriplegia; how to find good care and the means to pay for it; sources of information and services; and a short list of books and periodicals. 16 pages; available from source no. 1; 1-49, 50 cents each; 50-99, 35 cents each; 100 & over, 25 cents each.
- **NEW ELEMENTS IN EDUCATION-TRAINING PROGRAMS FOR SEVERELY DISABLED PERSONS: INFORMATION TECHNOLOGY, OPEN LEARNING, AND THE COMMUNITY COLLEGE** by Thomas R. Shworles and Phyllis M. Cunningham. An annotated bibliography, presented at the 1975 NPF Convention. Five categories, 86 entries, abstract, 29 pages mimeo; available from source no. 1; \$2.00.
- **NPF CONVENTION JOURNAL, 1975** published by National Paraplegia Foundation as a guide to the annual convention. Also has introduction to paraplegia and NPF; NPF history; NPF's research activities; NPF directory; NPF awards; PVA awards, wheelchair sports; and pertinent advertising. Available while supply lasts from source no. 1; \$1.00 for handling and mailing.
- **PARAPLEGIA LIFE (FORMERLY SQUEAKY WHEEL)** edited by Jim Smittkamp, published by National Paraplegia Foundation. NPF's official publication with articles on SCI related scientific matters, research, barriers, rights, chapters, SCI treatment, new products, opinion columns, reports of NPF officials, news briefs, and pertinent advertising. Published bi-monthly; 32 pages; available from source no. 1; included at no extra charge to NPF members; \$4.00 annually to others; \$6.50 foreign; 5 copies to one address, \$16.00; 10 copies to one address, \$25.00; gift subscriptions, \$4.00; single copies, \$1.00; back numbers (PL only), \$1.25.
- **PARAPLEGICS DISCUSS THEIR SEXUALITY** — published by National Paraplegia Foundation as a selected reprint from "Continuing Education in the Treatment of Spinal Cord Injuries - II", 1972. A frank discussion among three couples, disabled males and non-disabled females, about their sexual problems and how they handled them. 11 pages; available from source no. 1; \$1.00 each.
- **PROCEEDINGS OF SEMINAR ON NURSING CARE OF SPINAL CORD INJURIES (1975)**, published by National Paraplegia Foundation. Covers acute care, respiratory management, kinetic nursing, sexuality, patient and family, pediatric client, intermittent catheterization, skin care, discharge planning. 96 pages; available from source no. 1; \$5.00 per copy.
- **RETURN TO SOCIETY** edited by Jan Little from

proceedings of Allied Health Professions Workshop (1971). Discussion of the total rehabilitation of spinal cord injuries by M.D.'s, R.N., P.T., O.T., social worker, paras and quads. 26 pages mimeo; available from source no. 1; \$1.00 per copy.

- **SEX, REHABILITATION'S STEPCHILD - DEVELOPING PROGRAMS OF SEXUALITY WITH THE SPINAL CORD INJURED** — proceedings of a workshop at 1973 NPF Convention, published by National Paraplegia Foundation. Cosponsored by Allied Health Professions Committee, NPF, and Schwab Rehabilitation, Chicago. To provide guidance in establishing programs on sexuality for the spinal cord injured. Available from source no. 1; \$2.50 per copy.
- **SPINAL CORD INJURY HOPE THROUGH RESEARCH** — published by National Institutes of Health. A public information piece on paraplegics and spinal cord injury research (1971). Includes bibliography and glossary, 30 page booklet. Available from source no. 1 in single copies only, free; available from source no. 6, order DHEW Publication No. (NIH) 72-160, \$.20 each or \$15.00 per 100.

Publications available from Research Division Office

- **CNS REGENERATION BIBLIOGRAPHY: A BASIC REFERENCE** (Order #653-A) Historical Bibliography of Scientific Publications Relating to Regenerative Phenomena of the Central Nervous System, with emphasis on the Mammalian Spinal Cord. 1,969 references. The Bibliography comprises 3 sections: Part I-References prior to 1970 (927); Part II-References dated 1970 to original publication (June 1975); and Part III-Additional references researched as of November 1975. A valuable addition to every Neuroscientific Library. 140 pages. 8½ inch by 11 inch ring bound paperback. Author indexed of Parts I and II Price (postpaid) \$6.00 (U.S. and Canada) \$7.00 (Other Nations) Available from source no. 2.
- **NOTICES OF RESEARCH PROJECTS RELATED TO CNS REGENERATION (1974)** (Order #571) 239 abstracts of 189 Research Projects ongoing during the period 1971-1974 dealing with Central Nervous Regeneration, including related topics such as neural and glial development, growth and synaptogenesis, axoplasmic transport, reaction to trauma, metabolic and molecular changes, functional repairs, and human and animal paraplegia. Two volumes. \$25.00. Available from source no. 2.
- **NOTICES OF RESEARCH PROJECTS RELATED TO CNS REGENERATION (1975)** (Order #671) Abstract statements of 161 Research Projects funded in fiscal year 1975 dealing with Central Nervous Regeneration and related topics. Tabulations are included indicating funding by agencies and by primary area of investigation. Classifications include I. Investigations directly related to CNS Regeneration (1. Axonal elongation, 2. Collateral sprouting, 3. Intraaxonal transport, 4. Properties of neurons with damaged axons, 5. Synaptogenesis, 6. Biology of Neuroglia, 7. Development of systems, 8. Drug & hormone effects); and II. Investigations related to paraplegia or peripherally related to CNS Regeneration (9. Neural metabolism, physiology, & chemistry in the normal state, 10. Synaptic function, 11. Clinical applications & the physiology of paraplegia, 12. Peripheral regeneration, 13. Physiological & behavior studies of neuropathological conditions). Appendix includes comparison data for Fiscal Years 1972 and 1973. 263 pages 8½ x 11 ring bound paperback \$20.00. Available from source no. 2.
NOTE: Limited supplies of the following reprints are also available for postage and handling charge.
- **Axonal Regeneration and Functional Plasticity in the Central Nervous System.** Edited by Guth, L. (1974): *Experimental Neurology* 45: 606-654. (Order #598) Proceedings of the Third NPF Bien-

nial Conference on CNS Regeneration, May 13-15, 1974. Participants: S. Appel, A.I. Basbaum, S. Berl, J.J. Bernstein, J.B. Campbell, C.D. Clemente, S.M. Crain, B. Droz, N. Edalatpour, E.R. Feringa, M.E. Goldberger, M. Goldstein, B. Grafstein, A. Grinnell, L. Guth, T.W. Langfitt, G. Lynch, R.F. Mark, W.O. McClure, A.K. Ommaya, J.L. Osterholm, J. Semans, R.L. Sidman, D.B. Tower, N. Wessels, T.H. Williams, W.F. Windle, A.A. Zalewski. Price: \$3.00. Available from source no. 2.

- **Growth and Regeneration In the Central Nervous System. A report by the ADHOC Subcommittee of the Advisory Council of the National Institute of Neurological & Communicative Diseases & Stroke of the National Institutes of Health** (*Experimental Neurology* Volume 48, #3, September 1975, Part 2) Authors: S. Carter, L. Guth, F.W.L. Kerr, B. Grafstein, S.H. Appel, S. Varon, M. Saier, J.F. Kurtzke, R.L. Sidman, and N.K. Wessells. 251 pages \$3.00. Available from source no. 2.
- **NPF Aids and Abets Research** (Reprint from 1975 NPF Convention Journal) by Veraa, R.P. (1975). Describes History and Activities of NPF Research Division. 4 pages. Free. Available from source no. 2.
- **Physiological, Molecular, and Genetic Aspects of Central Nervous System Regeneration.** Edited by Guth, L., and W.F. Windle (1973); *Experimental Neurology* 39: iii-xvi. (Order #485) Proceedings of the Second NPF Biennial Conference on CNS Regeneration, May 1-3, 1972. Participants: A. Bjorklund, C.D. Clemente, R. Davis, M.R. Dimitrijevic, J.C. Eccles, J. Estable-Puig, R.W. Gerard, S. Gilman, B. Grafstein, J. Guth, T. Jahn, J.A. Kiernan, I. McDonald, R.Y. Moore, S. Ochs, S.L. Palay, F. Roisen, F.J. Samaha, R.L. Sidman, R. Sperry, U. Stenevi, S.S. Varon, P. Weiss, W.F. Windle, A.A. Zalewski. Price: \$2.00. Available from source no. 2.
- **Proceedings of the Conference: Continuing Education in the Treatment of Spinal Cord Injuries III.** (1973) (Order #425) Second Annual NPF Medical-Scientific Seminar, June 28-29, 1972. Participants: T.P. Anderson, H. Betts, P.C. Bucy, C.D. Clemente, T. Cole, J. Donohue, J. Garrett, M. Goldstein, J. Green, W. E. Hunt, R. Jackson, R.J. Meyer, T.J. Nugent, J.L. Osterholm, R. Sadik, E.S. Stauffer, J. Van Gilder, R.P. Veraa, R. White. Price: \$2.00. Available from source nos. 1 & 2.

Other Publications

LIED HEALTH

- **GUIDE TO WHEELCHAIR TRANSFER TECHNIQUES** — A thorough illustration of sitting and standing transfers. Developed in cooperation with the Colson Corporation. This production is designed to teach the patient ways to perform a wheelchair transfer to and from bed, toilet, tub, and car. Emphasis is placed on transferring safely with a minimum of exertion, and as independently as possible. Publ. no. 610, available from source no. 3, 35 mm filmstrip with 33 1/3 rpm record or audiocassette (indicate preference), 22 minutes, color, \$35.00; \$36.75, Int'l; Rental (record only), \$8.50.
- **A PROCEDURE FOR PASSIVE RANGE OF MOTION AND SELF-ASSISTIVE EXERCISES** — Directions for exercises used, under a physician's supervision to maintain joint motion. These slides are designed to present the techniques of passive range of motion and self-assistive exercises in such a way that nursing personnel can both learn it and teach it consistently to other staff members, patients, and families. Publ. no. 220, available from source no. 3, 85 b&w slides, \$42.50, \$45.00 Int'l; rental \$7.50.
- **BIOFEEDBACK IN NEUROMUSCULAR RE-EDUCATION** by Susanne Owen, Herschel Toomin, and Lyn Paul Taylor (1975) — published by Biofeedback Research Institute, Inc. Booklet features history, physical basis, uses of biofeedback in neuromuscular re-education for spinal cord injuries among others, biofeedback pro-

cedures, and references. 73 page booklet; available from Biofeedback Research Institute, Inc., 6325 Wilshire Boulevard, Los Angeles, CA 90048; \$5.50 per copy; \$4.50 to the physically handicapped.

- **MANUAL ON DYNAMIC HAND SPLINTING WITH THERMOPLASTIC MATERIALS - LOW TEMPERATURE MATERIALS AND TECHNIQUES** by Maude H. Malick, OTR. For use by physician, occupational therapist, physical therapist and orthotist. 197 pages, illustrated; available from Harmarville Rehabilitation Center, Ridge Road, Pittsburgh, PA 15238; \$10.00.
- **MANUAL ON STATIC HAND SPLINTING - NEW MATERIALS AND TECHNIQUES** by Maude H. Malick, OTR. For use by physician, occupational therapist, physical therapist and orthotist. About 110 pages, illustrated; available from Harmarville Rehabilitation Center, Ridge Road, Pittsburgh, PA 15238; \$6.00 each.
- **QUADRIPLEGIC FUNCTIONAL SKILLS FILM** — "Dressing", 17 1/2 minutes, demonstrates various methods used by quadriplegics to achieve independence in dressing. It also includes discussion of some problems encountered in adjustment to disability and in rehabilitation. Based on experience at University of Illinois Rehab-Educa. Center. M-3059-X; free short term use; purchase: \$70.25; available from source no. 7.
- **QUADRIPLEGIC FUNCTIONAL SKILLS FILM** — "Showering and Grooming", 15 1/2 minutes, demonstrates methods of achieving independence in personal hygiene by quadriplegics. It shows transferring to and from wheelchair to shower seat in tub and stall shower, bathing, shaving, dental and hair care. It also includes discussions of some problems encountered in adjusting to disability and rehabilitation. Based on experience at the University of Illinois Rehab-Educa. Center. M-3061-X; free short term use; purchase, \$66.00; available from source no. 7.
- **QUADRIPLEGIC FUNCTIONAL SKILLS FILM** — "Driving", 18 1/2 minutes, demonstrates various methods quadriplegics can use without assistance in transferring to and from a car and getting a wheelchair in and out of a car. It briefly covers driving with hand controls and adaptations. Included are two different types of power lift vans and a power winch for aid in putting a wheelchair into a car. Based on experience at University of Illinois Rehab-Educa. Center. M-3062-X; free short term use; purchase, \$75.75; available from source no. 7.
- **RANGE OF MOTION EXERCISES: KEY TO JOINT MOBILITY** by Patricia Toohey and Corrine W. Larson (1968) — Intended to assist nurses in geriatric institutions, nursing homes, extended care facilities, chronic disease units, and acute hospitals. Step-by-step procedures, with photographs, are given for a variety of exercises: passive, active, active assistive, and active. The manual is especially designed for the nurse who works without benefit of a physical therapy department or consultant services. Publ. no. 703, \$2.00, \$2.10 Int'l; available from source no. 3, 39 pages.
- **WHEELCHAIR SELECTION: MORE THAN CHOOSING A CHAIR WITH WHEELS** by Beverly Fahland (1967) — Fully illustrated guide to selection of a wheelchair to meet individual needs. Includes discussion of factors that must be considered in developing a wheelchair prescription. Detailed information on wheelchair types, sizes, and alternative features, as well as suggestions on wheelchair handling and maintenance are given. Publ. No. 713, available from source no. 3, 54 pages, \$2.00, \$2.10 Int'l. Int'l.

MEDICAL

- **SPINAL CORD INJURIES** edited by Daniel Ruge (1969). Written by physicians, all specialists with experience in spinal cord injury. 236 pages, illustrated; available from Charles C. Thomas, Publisher, Springfield, Illinois 62703; \$12.75.

NURSING

- **A LITTLE EXTRA CARE** — This series can be used in schools or for employees that serve the public, such as restaurants, hotels, airlines, and theaters. It covers seven types of physical handicaps, listing considerations that should be made for handicapped guests. The need for the use of common sense and good judgment is stressed in catering to these people. The slide series is supplemented by a booklet that re-emphasizes the main points in the slides. It is recommended that enough booklets be purchased to distribute to each member of the audience for permanent review of the information in the slide series. Publ. no. 290, available from source no. 3, 61 color slides with audiocassette (audible and inaudible signal), \$45.00; \$47.70, Int'l; extra booklets, \$.50 each, minimum extra book order - 10.
- **AMBULATION GUIDE FOR NURSES** by Patricia Ulrich and Lois Sorenson (1974) — Practical information to aid the nurse in caring for patients who are learning to ambulate. Designed for use as a reference as well as a text. Publ. 707, available from source no. 3, 66 pages, \$2.25, \$2.35 Int'l.
- **BASIC POSITIONING** — Demonstrates methods of preventing complications through correct positioning techniques. Supine, prone, side-lying, and sitting positions are outlined. This presentation is based on the premise that with good nursing care, many problems can be avoided; e.g., limitations in joint motion, contractures, and the development of pressure sores. Publ. no. 611, available from source no. 3, 35mm filmstrip with 33 1/3 rpm record or audiocassette (indicate preference), 11 minutes, color, \$30.00; \$31.50, Int'l; Rental (record only), \$6.50.
- **BASIC POSITIONING PROCEDURES** by Catherine H. Coles and Doris Bergstrom (1971) — Principles, techniques, and equipment used for positioning patients in a general and rehabilitation setting. A full discussion of assessing individual patients and forming positioning plans to meet their specific needs is presented. Techniques and equipment are illustrated. Directions for constructing and obtaining certain pieces of equipment are given. Publ. no. 701, available from source no. 3, 26 pages, \$1.65, Int'l, \$1.75.
- **BED POSITIONING** — Methods for positioning on a high-low bed with rehabilitation adaptations are demonstrated. More specifically, bed positioning techniques for patients with no restrictions of head or trunk motions are shown. Supine, side-lying, prone, and bedpan positions are outlined. Publ. no. 210, available from source no. 3, 20 color and 3 b&w slides, \$11.00, \$11.50 Int'l; rental \$4.50.
- **BEDS AND BED EQUIPMENT** — The Foster Reversible Orthopedic Bed, Circoelectric Bed, and the standing bed are special types of beds described in this slide set. Also viewed is the high-low bed with rehabilitation adaptations. Some of these adaptations include a high-low bed-frame with bedboard and footboard attached, an adjustable footboard, 4-inch mattress of 34 pound compression ratio sponge rubber, short and long side rails, and alternating pressure pads. Publ. no. 261, available from source no. 3, 14 color slides, \$7.00, \$7.50, Int'l.
- **BOWEL MANAGEMENT - A MANUAL OF IDEAS AND TECHNIQUES** — Some paraplegics and quadriplegics have not yet acquired adequate knowledge of bowel training and it is recognized that there are many who have never had the opportunity to learn some of the methods being taught and used successfully in rehabilitation centers. Includes: Methods to facilitate bowel evacuation; medications sometimes utilized as part of a bowel management program; considerations such as frequency, timing, diet, water intake, exercise, use of laxatives, position, use of medications, toilet aids, and cleaning; programs from three rehabilitation centers; ideas from ACCENT readers. Available from source no. 5, \$3.50.

Special Article

The Current Status of Research on Growth and Regeneration in the Central Nervous System

Summary of a Subcommittee Report Commissioned by the National Advisory Council of the National Institute of Neurological and Communicative Disorders and Stroke, 1975.

Subcommittee members:

Dr. Sidney Carter (Chairman)
Dr. Stanley H. Appel
Dr. Bernice Grafstein
Dr. Lloyd Guth
Dr. Frederick W. L. Kerr
Dr. Walle J. Nauta

Mr. Alan A. Reich
Dr. Richard L. Sidman
Dr. Silvio Varon
Dr. Eugene Streicher (Executive Secretary)

The impetus for the study of regeneration in the spinal cord and brain arises from the hope of alleviating the suffering caused by injury to the central nervous system, which afflicts millions of people throughout the world. In the United States alone, for example, there are now approximately 100,000 victims of traumatic spinal cord injury, and nearly 10,000 new cases occur each year. Nearly half of these patients develop complete permanent paraplegia or quadriplegia, and most of them are relatively young, the victims of accidents and bullet wounds, who must look forward to long lives of anguish and frustration for themselves and for the family and loved ones who care for them. The possibility that research on regeneration might lead to success in bringing about repair and restoration of function in damaged central nervous tissue offers hope not only for the victims of spinal cord injury, but also for those suffering from other disorders such as stroke (2 million patients in the U.S.), multiple sclerosis (0.5 million), and head injury (3 million).

The economic cost to society of these disorders cannot be calculated with any degree of accuracy. However, like the human suffering, it is overwhelming. At a minimum, the cost of spinal cord injury in the United States is

estimated to exceed 2 billion dollars annually (10,000 new cases annually times 30,000 dollars for the initial treatment equals 300 million dollars; annual direct expenses and loss of income by the present 100,000 cases, according to insurance company estimates, is over 2 billion dollars). Total annual cost of all the disorders which would be alleviated by the eventual success of research on central nervous system regeneration could easily exceed 10 billion dollars in the U.S. Conservatively speaking, savings could exceed 25 billion dollars annually on a worldwide basis. Thus, both in human and in economic terms, the effort applied to research on this problem appears to offer an extremely high return on investment.

In order to evaluate the current status of research on regeneration in the central nervous system and identify those areas of research where opportunities exist for significant advance, the Director of the National Institute of Neurological and Communicative Disorders and Stroke (NINCDS) appointed an *ad hoc* subcommittee of the NINCDS National Advisory Council. This subcommittee was charged with reviewing and evaluating the status of research in this area and advising the Council on current and future research needs and appropriate methods of meeting these needs. The following is a summary of the highlights of the subcommittee report. The scientific aspects of the report have been published in *Experimental Neurology* (1975, Vol. 48, No. 3, Part 2, 251 pp.); reprints are available from the NINCDS. The administrative aspects of the report are now under consideration by the officers of the NINCDS and NIH.

Published at the request of the National Institute of Neurological and Communicative Disorders and Stroke.

Reprint Requests: Dr. Murray Goldstein, Associate Director, National Institute of Neurological and Communicative Disorders and Stroke, Bethesda, MD 20014.

Historically, the problem of repair of damage to the human central nervous system has been considered to be extremely difficult, if not impossible, to solve. Adult nerve cells, once destroyed, are never replaced, and the only kind of repair that might be anticipated is the regrowth from partially damaged nerve cells of the protoplasmic strands (axons and dendrites) that normally link one nerve cell to another. Indeed, in the peripheral nervous system, after correct neurosurgical treatment, damaged axons will regrow and eventually re-establish some functionally useful connections. Even this limited degree of repair, however, is not seen within the central nervous system. Here nerve fiber outgrowth is usually abortive and large numbers of nonneuronal cells accumulate at the site of the damage, causing mechanical obstruction and compression of any fibers that successfully find their way through the damaged region. Recognition of the influence of mechanical factors on nerve fiber outgrowth led to some attempts to facilitate such outgrowth by providing a suitable mechanical support for the growing fibers, but the goal of functional recovery has never been achieved.

Until recently, this bleak picture of the prospects for recovery from central nervous system damage has dominated medical thinking. In the last few years, however, new developments in the field of neurobiology as well as the re-evaluation of some previously held ideas, have led to a clearer appreciation of the problems involved in central nervous system repair. Important advances have been made in finding new experimental systems in which nerve growth can be studied, and in analyzing the properties of nerve cells during regeneration and developmental growth. These advances have resulted in a great deal more optimism about the possibilities of eventually finding the techniques required to deal successfully with the damaged central nervous system. This goal is not likely to be achieved by a sudden scientific "breakthrough," but by the gradual accumulation of data and development of ideas in many different areas, some of which have only recently come to be recognized as important sources of basic information about central nervous system regeneration.

In the past, the peripheral nervous system has served for the study of regeneration, and this system continues to be a source of important new insights into the regenerative process. However, an important trend in current research is to focus more directly on the properties of the central nervous system itself. Considerable attention is being given, for example, to the central nervous systems of lower vertebrates, where vigorous regeneration occurs, culminating in the restitution of function. These systems therefore offer the opportunity for studying not only regeneration but also the more specialized processes leading to selective reconnection of the regenerated fibers. Such mechanisms are for the most part lacking in the adult forms of the higher vertebrates, but recently one central system in adult mammals has been identified which appears to be capable of regenerative growth, namely the aminergic system of the brain. While most central neurones do not show this kind of regenerative

response to direct injury, they are nevertheless capable of outgrowth, as indicated by the sprouting of intact nerve fibers near a lesion in the central nervous system. Although this process of collateral sprouting often results in the formation of functionally inappropriate connections, it can provide useful insights into mechanisms involved in the initiation of axonal outgrowth and the establishment of synaptic terminals; moreover the very fact that collateral sprouting occurs reveals that the central fibers have a growth capacity which might be exploitable also for regenerative repair. Another area of promise is the field of tissue culture of brain fragments or nerve cell suspensions; this technique offers the possibility of studying axonal growth and nerve cell development under direct vision and with a great degree of control over the nerve cells' chemical and physical environment. Finally, studies of developing nervous systems have been receiving increasing attention, first, because the embryonic and neonatal nervous systems of higher vertebrates have repair mechanisms that the adults lack, and second, because the changes occurring during development may disclose the factors that control the sequential assembly of complex functional arrays of neurons.

With the development of the above systems and techniques, an increasing number of investigators has been drawn to problems of growth and regeneration in the nervous system. Some of the topics of greatest interest at the present time and the directions in which they are likely to lead are as follows:

Reaction of the Nerve Cell Body to Injury. Damage to the axon results in profound metabolic changes throughout the entire nerve cell; some of these changes are supportive of axonal outgrowth, while others reflect a tendency toward increased degradation of cell constituents. An important objective of studies in this area is to find means for maximizing the supportive events and suppressing the degradative ones.

Trophic Interactions. Among the factors that promote the growth of the nerve cell are chemical influences from neighboring cells. Glial cells, for example, play a role not only in maintaining the nerve cell but in determining specific patterns of association among neurons; trophic interactions among nerve cells are evident from the fact that when one nerve cell makes contact with another, the well-being of both partners improves, as indicated, for example, by increased size of both. The nature of the materials that might pass from one cell to another in these circumstances is still unknown, but it is obvious that their identification would enable us to develop important pharmacological techniques for counteracting the deleterious effects of injury and enhancing axonal outgrowth.

Nerve Growth Factor. This protein, which has now been chemically defined, promotes the growth of sensory and autonomic neurons both in tissue culture and in intact animals, and it might be one of the factors which participate in the trophic interactions described above. Furthermore, this particular substance may prove to be but one representative of a family of growth-stimulating

agents affecting different classes of neurons. Studies of this factor therefore point toward the possibility of analyzing the mechanisms that enhance nerve growth, as well as the possibility of discovering similar agents with a wider range of effective targets.

Axonal Transport. The movement of materials from their sites of synthesis in the cell body to their sites of utilization in the outlying portions of the nerve cell has long been recognized, but only recently have scientists become aware of the importance of this transport in the maintenance of function in both normal and regenerating nerve cells. In the regenerating cell, axonal transport plays a key role in conveying materials necessary for the formation of the new axon and may also be involved in sending information to the cell body about the status of the axon. The nature of the transported materials and the way in which the synthesis and supply of structural elements is regulated are obviously key issues toward which work in this area is directed.

Axonal Elongation. Tissue culture studies have made possible detailed investigations of the behavior of the axonal membrane during axonal outgrowth. Characteristic alterations in axonal contour have been identified, and even subtle alterations in the chemical composition of the nerve tip membrane have been detected. Elongation has been modified by changing the composition of the medium in which growth was occurring, indicating the importance to regeneration of extrinsic factors in the immediate environment of the nerve tip. Such extrinsic factors also appear to influence axonal outgrowth in the intact animal during development or regeneration. Thus the process of axonal elongation, the agents that facilitate such outgrowth, and the factors that inhibit elongation when an appropriate terminal site is approached, are important topics under current investigation.

Selective Reinnervation. Studies on lower vertebrates have provided persuasive evidence that axonal growth in the central nervous system is highly directed and selective. The mechanisms by which such selectivity is achieved presumably also operate in the establishment of connections in the embryonic nervous system of higher vertebrates. These mechanisms would have to be remobilized to achieve restoration of function in regenerating nervous tissue. The nature of these mechanisms is still a subject for speculation, and answers are being sought through attempts to determine the genetic constraints as well as the cellular and molecular factors in the local environment that influence intercellular recognition, aggregation and adhesion.

Development of Synapses. The formation of a synaptic junction involves a modification of both the nerve tip and the cell with which it makes connection. This process probably involves a series of steps in which each of the partners influences the other. Analysis of this process should ultimately lead to discovering both the means for enhancing this process and the means for discouraging the formation of inappropriate synapses that might interfere with recovery of function.

Functional Plasticity. It is well known that recovery

from the effects of injury to the nervous system is much more rapid in young animals than in adults. This is in part due to the greater capacity for repair of the immature nervous system by means of the mechanisms described above. There are some indications, however, that additional factors may make the developing system more susceptible to functional influences (e.g., patterns of use and disuse). Further exploration of this problem will show whether such functional plasticity can be re-evoked in connection with regeneration in the adult, and whether it can be suitably controlled to provide for an enhancement of functional capacity following regeneration.

It is evident that in the exploration of the various avenues outlined above, the question is no longer whether central nervous system damage can regenerate, but what are the circumstances that are likely to lead to such regeneration and to recovery of function. It is clear that efforts must be concentrated on overcoming two major hurdles: one is to induce the central neurons to grow; the other is to insure that the growth results in the establishment of appropriate and functional synaptic connections. Direct medical intervention in cases of damage to the human nervous system must therefore be viewed as an accessible goal which requires further basic knowledge on which to build appropriate therapy. Although this information is not yet at hand, recent advances have been sufficiently encouraging to justify increasingly vigorous research efforts.

A number of recommendations have been made in the report of the subcommittee in order to maintain and accelerate the investigative momentum, and thereby to bring us closer to a solution of the problem of central nervous system regeneration. These recommendations point out research areas of high priority and opportunity, as indicated above. In addition, the report emphasizes the need for additional research training programs in areas such as the developmental neurosciences and the neuropathology of trauma to the central nervous system. Methods for increasing NINCDS activities in program planning, program development and program coordination are suggested in the report, with the expectation that a focused national effort could do much to accelerate both the development of needed fundamental information and its translation into clinically useful application.

The scientific inquiry into the enigma of regeneration in the central nervous system is at such an early stage that, as has been the case with other scientific discoveries, freedom of scientific investigation is essential to ensure the necessary creativity in such a highly complex, multidisciplinary effort. There are no substitutes at this stage for the innovative insights that independent thinking and experimentation can provide. The rate of scientific advance might be enhanced, however, by the formation of a permanent committee, which would act as "custodian" of the research effort in this critical area, and would actively promote research and monitor scientific progress while respecting the requirement for freedom of scientific inquiry and encouraging individual creativity.

Such a committee, by being sensitive to both the human need for an eventual cure and to the advancement of science, could help to insure the proper balance, at each stage of progress, between direct research in regeneration in the central nervous system and relevant research in peripheral areas; it would encourage a multidisciplinary approach; it might advocate priorities. With an all-embracing concern for progress, the committee would: stimulate appropriate, healthy competition; promote teamwork to achieve synergism; encourage relevant international involvement; heighten public consciousness of the problem; advocate support for appropriate lectureships and fellowships, conferences,

articles, and workshops; strengthen the effort of pertinent voluntary health agencies and promote cooperation among them; insure recognition of outstanding work; and urge appropriate public and private support.

At its meeting on March 21, 1975, the National Advisory Neurological and Communicative Disorders and Stroke Council reviewed and accepted with enthusiasm the report and recommendations of its *ad hoc* Subcommittee on Growth and Regeneration in the Central Nervous System. A copy of the report is available from Dr. Murray Goldstein, director of the Stroke and Trauma Program, NINCDS, Bethesda, MD 20014.

NINDS COUNCIL AD HOC SUBCOMMITTEE ON GROWTH AND REGENERATION
IN THE CENTRAL NERVOUS SYSTEM

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Professor of Neurology
College of Physicians and Surgeons
New York, New York

Dr. Stanley H. Appel
Professor of Medicine
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Durham, North Carolina

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Staff Scientist, NINDS
Extramural Programs
Bethesda, Maryland



DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE
PUBLIC HEALTH SERVICE
NATIONAL INSTITUTES OF HEALTH
BETHESDA, MARYLAND 20014

March 8, 1976

Honorable Philip A. Hart
United States Senate
Washington, D.C. 20510

Dear Senator Hart:

Your memorandum of February 25 and the correspondence and enclosures from Mr. Matthew St. Jean, Pascoag, Rhode Island, regarding spinal cord injury, have been referred to this Institute for reply. The National Institute of Neurological and Communicative Disorders and Stroke (NINCDS) conducts and supports the Government's research in this area.

We are sorry that Mr. St. Jean suffered a severe spinal cord injury and can certainly understand his interest in research which may be of potential benefit to him and other paraplegics.

As further evidence of the Institute's interest in this area, an Ad Hoc Subcommittee of its Advisory Council recently completed an evaluation of the current status of regeneration research and identified those areas where potentially significant advances might be expected. The Subcommittee's full report has now been distributed to almost all of the leaders in this research area and is expected to stimulate further research on regeneration. A copy of the report is enclosed.

The material enclosed in Mr. St. Jean's letter to you relates to Mr. Roger Frank, Portland, Oregon, and the surgery that was performed on him in the U.S.S.R. We would like you to know that Mr. Frank's father has been in touch with us from time to time about his son's case. Through correspondence and a personal visit to this Institute by Mr. Frank, we learned that he took his son to Russia for a new enzyme treatment which Soviet scientists are reported to be using experimentally in spinal cord injury cases. This is a medical rather than a surgical treatment. As reported by the Soviets, it is for application to the acutely injured patients within the first few hours after injury. In Mr. Frank's case, however, it was determined that an operation was necessary, and this was performed. Soviet scientists have indicated that this operation did not involve any techniques unknown in this country.

In the ensuing months, we have had many inquiries from spinal cord injury victims or their families regarding surgical treatment in the Soviet Union. We have urged all of these people to seek expert advice

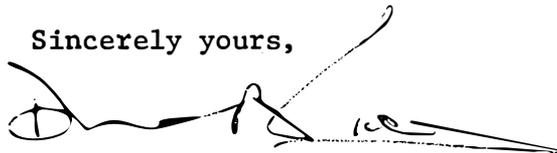
within this country before contemplating a trip to the U.S.S.R. because the types of neurosurgical treatment available there are not different from those available at centers within the United States. A representative list of well staffed, well equipped centers is enclosed.

In regard to the experimental enzyme therapy mentioned above, the Soviet proponents themselves emphasize that this is only for the acute, immediate post accident period and not for the stabilized injured patient months or years after the accident. The NINCDS is currently evaluating the reports by the Soviet scientists and the potential therapeutic uses for the experimental therapy.

Also, for some time the Institute has been working on plans to bring Professor Levon A. Matinian, Orbeli Institute of Physiology, Academy of Science, Armenia SSR, in Yerevan, to this country for a conference with U.S. experts in the field of spinal cord injury. Dr. Matinian is a neuroendocrinologist whose research has provided the basis for the medical treatment described above. Now, because of the great interest generated by Roger Frank's case, an invitation also has been extended to the USSR Ministry of Health to send a number of appropriate scientists from the Polenov Institute where Mr. Frank was treated. Arrangements are being made through the Office of International Health, Public Health Service. It is anticipated that the conference will take place some time in May.

We hope this information will help to assure you and Mr. St. Jean of the interest of the Government in research on spinal cord injury and nerve regeneration. If I can provide you with additional information about the programs of the NINCDS or assist you in any other way, please let me know.

Sincerely yours,



Donald B. Tower, M.D.
Director
National Institute of Neurological and
Communicative Disorders and Stroke

4 Enclosures



By Harry Nalchayan—The Washington Post

Soviet Drs. V. M. Ugryumov, E. I. Babychenko and Levon A. Matinian examine Greg Bedan, 15, of Greenwood, Ind.

EXHIBIT 7

The Soviet Approach to Paralysis

Visiting Doctors Believe the Body Can Compensate for Injuries

By Stuart Auerbach
Washington Post Staff Writer

In the unlikely setting of an embassy reception room, three Soviet doctors bent over 15-year-old Greg Bedan of Greenwood, Ind., yesterday, seeking signs that their specialized treatment could ease his paralysis.

He was the first of four Americans that the Soviets, who are specialists in paralysis caused by spinal cord injuries, talked to or saw at the embassy facility yesterday. The specialists are in this country to address a scientific conference and tour medical treatment centers.

The Americans, including a Federal Communications Commission commissioner whose son is paralyzed, had been drawn to the Soviet doctors by reports that they offered treatments that far surpassed anything available here.

The specialists said they believe in the aggressive use of surgery as soon after the injury as possible to relieve pressure on the spinal cord and allow the body's regenerative process to work.

The head of the delegation, Dr. V.M. Ugryumov, director of the Polenov Neurological Research Institute in Leningrad, said Soviet doctors believe more strongly than their Western colleagues in the ability of the body to adapt and compensate for injuries to the spinal cord. While this approach doesn't guarantee a complete cure of the paralysis, it often allows greater movement of limbs and other bodily functions, he said.

The reports of the Soviet successes were spread to other paraplegics (persons with paralysis of the lower half of the body) in this country by

Roger Frank, 21, of Portland, Ore., who revealed in news interviews that he had regained bladder control and some sensation in his legs after an operation last year in Leningrad.

But in the four cases they discussed yesterday, the Soviet specialists praised the care given by the American doctors, and said there was nothing more they could do.

Those were hard words for the Americans to hear, and in some cases—despite their sharp translation into English—the words were barely understood.

There are 125,000 to 150,000 Americans paralyzed by spinal cord injuries, and about 7,500 patients are added to the list each year. The treatments, however, have not kept pace with the number of new cases caused mainly by accidents on highways, in swimming pools and on athletic fields.

Greg Bedan, for example, was injured in a football game two years ago. He landed on his head making a tackle and immediately lost the use of his arms and legs.

At the request of the Soviet doctors, Greg's parents, Jack and Anne Bedan, lifted him from his wheelchair onto a black leather couch. With practiced ease, they undressed him for the examination.

Dr. E. I. Babychenko, a professor of neurosurgery at the Saratov Medical Institution, tested for feeling in Greg's arms and legs—moving them gently pinching them and moving a matchstick across his stomach to check for a tickling sensation.

Ugryumov used a rolled-up piece of paper to test eye reflexes, while Dr. Levon A. Matinian of the Gelviti Insti-

tute of Physiology in Yerevan, Soviet Armenia, watched.

After their examination, the Soviet doctors gave the Bedan family the sad news. "Right now," Ugryumov said, "your main hope is rehabilitation treatment. Your most important task is that you adapt yourself to life."

"As specialists we have a duty to speak candidly. The amount of damage has been so intensive that there is no opportunity for regeneration."

Still, the Bedans pressed for some hope. Mrs. Bedan asked about treatments with enzymes that Matinian is experimenting with. He replied they are most successful when given immediately after an accident and that they don't work at all when the spinal cord damage is as severe as in Greg's case.

The examination of Laurie Becker, a 43-year-old auto dealer from Champaign, Ill., was almost a carbon copy of Greg's. Becker, too, hoped that he could be helped by a trip to Leningrad even though doctors there examining his mailed medical records and X-rays said there was nothing more they could do.

The Soviet doctors warned him against seeking more operations to relieve his pain. Operations, they said, could undo the natural healing process that allows him to keep on running his business.

FCC Commissioner Charlotte T. Reid, whose son, Tom, 33, is a patient in the Veterans Administration Hospital in Long Beach, Calif., came to see the Soviets because "I didn't want to leave any stone unturned."

They suggested further tests and asked her to send them the results and her son's X-rays. But again, they promised nothing.

13, 1973

Richard L. Sidman, M.D.

Bullard Professor of Neuropathology
Harvard Medical School
Chief, Department of Neuroscience
Mental Retardation Program
Children's Hospital Medical Center
Boston, Massachusetts

Statement on Central Nervous System
Regeneration--Basic Research

To: Labor-HEW Subcommittee of the House of Representatives
Committee on Appropriations
U.S. Capitol Building
Washington, D.C. 20515

EXHIBIT #8

Mr. Chairman and Honored Members of the Committee:

My name is Richard L. Sidman, of Brookline, Massachusetts. I received the M.D. degree from Harvard Medical School in 1955. From 1956 to 1959 I served as an officer in the Commissioned Corps of the U.S. Public Health Service at the National Institutes of Health, Bethesda, in the laboratory of Dr. William F. Windle, a pioneer widely honored for his research on central nervous system regeneration. Since 1959 I have been on the faculty of the Harvard Medical School and have engaged continuously in basic research on development of the mammalian central nervous system. As Bullard Professor of Neuropathology at Harvard since 1968, my goal has been to bring basic science to bear directly on mechanisms of disease in the nervous system. With acceptance in 1972 of an additional role as Chairman of the Department of Neuroscience in the Mental Retardation Program at the Children's Hospital Medical Center, I have a further opportunity and responsibility to focus research more sharply so that advances made in the laboratory can be brought as rapidly as possible to the direct benefit of the patient. I serve also on advisory committees to the National Institutes of Health and to several lay organizations concerned with special areas of health, including the Paraplegia Research Foundation--Paracure, Inc.

I come before you today out of concern for two sets of problems. The more important set concerns the devastating unsolved affliction of the hundreds of thousands of U.S. citizens suffering the consequences of severe injury to the spinal cord or brain. A less important, but still very real second set of problems confronts every American biomedical scientist today, since our work is being progressively inhibited by the current negative federal policies concerning research support.

My message, reduced to one paragraph, is as follows. Most diseases of the brain and spinal cord involve focal and permanent damage. Once the destruction has occurred,

we physicians can do nothing today; we treat only the resulting symptoms of paralysis, impairment of speech and vision, and so on. The desirable direct therapy would be through regeneration of damaged nerve fibers and reestablishment of functional connections. The diseases I am talking about range from many of the forms of mental retardation and cerebral palsy, to chronic multiple sclerosis, brain and spinal cord trauma, focal epilepsy, and most strokes. An extremely conservative estimate is that the population we are referring to with potentially treatable disease, if effective regeneration should become a reality, numbers at least 600,000 of the most severely affected patients in the United States. With no weapons but the presently available medical measures, the human suffering and economic consequences are immense and steadily increasing. The source of hope is that neurological science is at that special point today where we can mount a bold yet sensible laboratory research program on animals that has a fair prospect of yielding in time a practical method of regeneration in the human central nervous system.

Let us consider for a moment only one type of damage, the all-too-frequent injury to the spinal cord at the level of the neck that can result from a penetrating bullet, a football or diving accident, or an injury sustained while fighting for one's country. The personal tragedy is beyond comprehension. Most of these spinal disasters strike young men, age 18-25, often paralyze them (termed "quadriplegia" or "paraplegia", according to whether all four limbs or only the lower limbs are affected), remove all conscious sensation from the neck down, and sentence them to a half century in bed and wheelchair. The economic toll is staggering. The initial hospitalization costs, an average of \$50,000 - \$250,000 per patient, and the bills continue for life at thousands of dollars per year. The recent extension of Medicare benefits to the permanently disabled under age 65 will add significantly to the federal health bill. Indirect costs in terms of lost earning capacity for the individual and reduced productivity for the nation are beyond my competence to calculate. Spinal cord injury is the most labor-intensive (man hours of care per patient) problem in all medicine, and labor costs are rising rapidly. The most plausible way, some would say the only way, to make a dent in this national economic disaster is to achieve effective regeneration of nerve fibers in the damaged tissue.

The scientist interested in basic research sometimes feels in an uncomfortable position when the issue of project-oriented research is raised. He or she knows that every field of knowledge has its periods of excitement and its slack periods. Basic work on the nervous system is currently in a marvelously exciting phase. Many of us recognize an analogy with the ferment in molecular biology in the late 1940's and the

50% that led to such marked advances in the physician's understanding of genetic and metabolic diseases later in the 1960's and 70's. That development is universally acknowledged to have resulted directly from the Congress' wisdom in developing a bold health research policy and pressing the National Institutes of Health to implement it and maintain its high quality through a uniquely effective peer review system. Now, at the very time when we can foresee a comparable development on the horizon for diseases of the nervous system, when scientists in increasing numbers wish to become trained to deal with key challenges such as the questions of how nerve cells grow, how they make such fantastically intricate connections, and what stimulates them to regenerate when injured, the government is setting policies that choke off training and research. Congress, it appears to those of us on the outside, has abdicated its former role of leadership. We hope this is only temporary.

Let me elaborate a bit further on the biomedical scientist's view of this. We have two major anxieties. One is that research is being strangled and we are being told in effect to go out and deliver medical care instead. In the neurological field and in most other branches of medicine, this is senseless. A few major neurological diseases such as polio have been solved so well that there is virtually no problem any longer. However, most neurological diseases are treatable only in unsatisfactory terms--maintenance of flexible joints in a paralyzed limb or prevention of bedsores in a paraplegic patient, for example. What the biomedical scientist can contribute uniquely is new knowledge about the principles and mechanisms of growth that one day will allow the physician to coax injured nerve cells to regenerate effectively and restore normal function. We cannot afford to throw away this role. The second anxiety is that research will be forced by government to focus on problems that are admittedly important, but that are not ripe for solution. Scientists may seem to be far-out types with no sense of priorities, but actually the exact opposite is true. We are intensely pragmatic, and hardly ever will show interest in an idea unless there is some good way to test it directly in the laboratory. We feel that we simply cannot put money to good use in the direct study of certain important diseases for lack of the basic information necessary to design a laboratory experiment that answers a definite question. That is the source of our cry for support of basic research, and we feel intensely that the progress of medicine over the past 25 years bears witness to the validity of our view.

Now the current importance of research on growth and regeneration in the nervous system, and the reason I advocate this topic as vigorously as I do, is that it casts

the legitimate popular need that we come to grips with destructive diseases of the nervous system and also the scientist's need to receive funding for those fundamental biomedical problems that are attackable in a realistic way. Nervous system growth and regeneration is people-oriented and involves good medicine, good economics, and good science.

I would like to make two specific policy suggestions for this committee to consider.

1. Task Force on Nervous System Growth and Regeneration. Creation of such a Task Force, representing the national biomedical community and administered through the National Institute of Neurological Diseases and Stroke, was recommended in testimony before Congress a year ago. Its charge was to assess the need in terms of manpower, goals, and quality of scientific ideas, and to recommend a long range policy for future funding. It was hoped that the completed report of this Task Force would have been available to the government in time for the coherent planning of the budget for Fiscal Year 1974 and subsequent years. The idea of this Task Force was accepted by the Department of Health, Education, and Welfare, largely through the initiative of the Paraplegia Research Foundation--Paracure, Inc., in September, 1972, but its implementation by the National Institute of Neurological Diseases and Stroke has been hampered in the past several months by legislative constraints. The new Public Law 92-463 was intended to provide greater public visibility in federal decision, but it seems to be serving to inhibit the Institutes from obtaining much needed expert advice from the nation's scientists. No governmental agency can function effectively in isolation, as we have all been learning painfully through recent newspaper headlines.

I urge Congress to take steps to remove these constraints so that the National Institutes of Health can continue to obtain the wisest outside advice and to direct the NIH to organize this particular Task Force at last, after so much undesirable delay.

2. Specific Appropriation. I urge inclusion in the FY 74 budget of a line item for basic research on growth and regeneration in the nervous system in the amount of 4.5 million dollars. This item should be separate from and in addition to the regular budget of the National Institute of Neurological Diseases and Stroke, but it should be administered by that Institute and awarded on the basis of peer review advice. A suggested breakdown of this fund, allowing for modification in detail according to the response from the nation's scientific applicants, would be as follows:

5 invited major programs at an average annual cost of \$400,000 each	\$2,000,000
10 projects at an average annual cost of \$200,000 each	2,000,000
10-20 special research grants at an average annual cost of under \$50,000 each;	<u>500,000</u>
	\$4,500,000

The major programs and projects should be ones that integrate a range of laboratory techniques and focus them on basic problems of growth and regeneration. Examples of pertinent subjects ripe for exploitation toward the eventual practical goal of regeneration in the spinal cord and brain of man, are 1) electron-microscopic definition of nerve cell and nerve fiber behavior during fiber growth leading to formation of the "wiring" connections that allow the nervous system to function; among other things, this is coming to involve the development and use of new computer instrumentation to allow reconstruction and quantitative measurement of three-dimensional images of growing cells; 2) fluorescence microscopic methods for visualizing very fine caliber regenerating nerve fibers of defined chemical classes; 3) new tissue culture methods for growing partially differentiated brain and spinal cord cells of neuronal and glial types, to allow more precise analysis of the cell interactions that underly maintenance, growth, regeneration, and connectivity; 4) grafting of cells into injured brain and spinal cord of experimental animals, on the basis of new knowledge of genetics and immunology, and new techniques of cell isolation; 5) basic and physical chemical analysis of growth-controlling molecules such as the protein called Nerve Growth Factor, and study of their mode of action; 6) analysis of the significance of downstream and upstream transport of specific classes of molecules possibly serving for the initiation and maintenance of growth and regenerative activity; 7) chemical study of the interaction of hormones and other small molecules with proteins at cell surfaces and in the cell cytoplasm and nucleus to influence ultimately the genetic program of growth and differentiation; 8) physiological study, mainly via microelectrode and iontophoretic experiments, of the role of active inhibition at the cell level in preventing normal functional activity after focal injury to the nervous system. This partial listing of the scientific scope should underscore the need for training of new professional personnel to a high level of skill, as well as the need for new programs, not currently funded anywhere in the country, that would provide the necessary integration around the focus of growth and regeneration. The largest of these programs should be asked to achieve integration with an academic clinical rehabilitation center so as to complete the bridging from laboratory bench to patient that has proved so successful a feature in the areas of modern medicine.

The small research grants also merit emphasis in the total plan. As Dr. James D. Watson, Nobel laureate, frequently points out, almost every important discovery, the ones that turn a science in a new direction, are made by young people, commonly virtual unknowns at the time they develop the key idea. Funding for such persons is

particulary crucial if paraplegics are to rise out of their wheelchairs one day, or stroke victims and epileptics are to recover fundamentally from their injuries.

One hears the criticism that we must not push such a research area because it will raise false hopes in the patients afflicted with nervous system injuries. In my experience this is not a realistic worry. The patients and their families do not expect overnight miracles. Also labor leaders and many political figures at the state and national level that I have talked to are aware that nothing is that easy. All of them feel strongly and simply that their government and the nation's scientists should be at work on the problem. If someone argues that it might take 100 years to find a cure, the patients reply that it will take that many years longer unless we get on with the job. They are depressed by inaction and indifference. They know that there is much basic work of extraordinary difficulty to be done, but they know that the neurosciences are among the most exciting and promising of all the sciences today. They say, "Let's put it all together," and we should respond.

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EXHIBIT #9

THE NATIONAL PARAPLEGIA FOUNDATION RESEARCH DIVISION MRS DURST
4440 NORTHWEST NINETEENTH ST
LAUDERHILL FL 33313

THIS MAILGRAM IS A CONFIRMATION COPY OF THE FOLLOWING MESSAGE:

3059238111 TDMT HOLLYWOOD FL 218 06-02 0322P EST
PMS PRESIDENT GERALD R FORD
WHITE HOUSE DC
2-035010E154 06-02 0207P EST

AT A CONFERENCE SPONSORED BY THE NATIONAL PARAPLEGIA FOUNDATION AT THE DIPLOMAT HOTEL IN HOLLYWOOD FLORIDA THIS WEEK FIFTY INTERNATIONALLY DISTINGUISHED SCIENTISTS CONFIRMED OUR BELIEF THAT AN INTENSIVE COORDINATED PROGRAM OF RESEARCH IN THE BASIC NEUROLOGICAL SCIENCES WOULD LEAD TO ENORMOUS CLINICAL BENEFITS TO OUR NATIONS TWO HUNDRED THOUSAND PARAPLEGICS AND QUADRUPLEGIAS AS WELL AS AN ADDITIONAL FIVE MILLION AMERICANS AFFLICTED BY OTHER DISORDERS OF THE CENTRAL NERVOUS SYSTEM.

SUCH A PROGRAM HAS BEEN OUTLINED IN DETAIL BY A SUBCOMMITTEE ON GROWTH AND REGENERATION IN THE CENTRAL NERVOUS SYSTEM COMMISSIONED BY THE NATIONAL INSTITUTE OF NEUROLOGICAL AND COMMUNICATIVE DISORDERS AND STROKE DATED MARCH SEVENTH 1975. THE COST FOR THE IMPLEMENTATION FOR THIS PROGRAM WOULD BE SMALL IN COMPARISON TO THE TWO BILLION DOLLARS THAT PARALYSIS COST OUR NATION EACH YEAR AND COUNTLESS ADDITIONAL BILLIONS INCURRED BY OTHER DISORDERS OF THE CENTRAL NERVOUS SYSTEM.

MR PRESIDENT, WE URGE YOU TO REAFFIRM YOUR COMMITMENT FOR SUPPORT OF THE IMPLEMENTATION OF THE RECOMMENDATIONS OF THIS SUBCOMMITTEE AS A SIGNIFICANT AND INDEED VITAL INVESTMENT IN THE FUTURE OF OUR NATION AND THE WORLD.
RESPECTFULLY

DON A OLSON PHD
PRESIDENT
NATIONAL PARAPLEGIA FOUNDATION

BERNICE GRAFSTEIN PHD
CHAIRMAN
SCIENTIFIC ADVISORY COMMITTEE
ON REGENERATION IN THE CENTRAL
NERVOUS SYSTEM

RICHARD P VERA
DIRECTOR
RESEARCH DIVISION
NATIONAL PARAPLEGIA FOUNDATION

CARMINE D CLEMENTE PHD CHAIRMAN SCIENTIFIC ADVISORY COMMITTEE
NATIONAL PARAPLEGIA FOUNDATION AND

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EXHIBIT #10

LYLE G TAYLOR
15515 52ND AVE WEST
EDMONDS WA 98020

THIS MAILGRAM IS A CONFIRMATION COPY OF THE FOLLOWING MESSAGE:

2067430887 MGM TDRN EDMONDS WA 257 03-23 0231A EST
ZIP
PRESIDENT GERALD FORD
WHITE HOUSE

WASHINGTON DC 20500

OUR 20-YEAR OLD SON MIKE IS PARALYSED FROM THE NECK DOWN DUE TO INJURIES RECEIVED IN MOTORCYCLE ACIDENT 2 YEARS AGO. THE BEST US MEDICAL DOCTORS TELL US THAT THEY CAN'T DO ANYTHING MORE FOR HIM. JUST RECENTLY WE LEARNED THAT SOME WORLD RENOWED NEUROSCIENTISTS FEEL THAT ANSWERS ARE AVAILABLE IF WE WOULD CHANNEL SOME REAL EFFORT AND MONEY INTO THIS RESEARCH. I HAVE JUST NOW LEARNED THAT N.I.H. TURNED DOWN A \$20,000 NATIONAL PARAPLEGIA REQUEST FOR FINANCING THE BIENNIAL NEUROSCIENTIFIC MEETING THIS MAY. THIS I FIND HARD TO UNDERSTAND WHEN MY WIFE AND I SPEND MANY HOURS EACH DAY, EVERY DAY OF THE YEAR TAKING CARE OF MIKE. HOW IS IT THAT WE CAN BUDGET MONEY FOR MANY THINGS THAT HAVE NO HUMANITARIAN EFFECTS WHATSOEVER, AND YET WE CAN'T FIND MONIES TO HELP THE SEVERAL HUNDRED THOUSAND PEOPLE SUFFERING FROM PARALYSIS, INCLUDING ALL OF THE PARALYSED VETERANS, SKIERS, BIKE RIDERS, RODEO RIDERS ETC. MR PRESIDENT, POLIO WAS CONQUERED BECAUSE A PRESIDENT ROSE TO THE CAUSE AND WE PUT MEN ON THE MOON BECAUSE PRESIDENTS BELIEVED, IN THIS BICENTENNIAL YEAR WILL YOU RISE TO THE CALL? MR PRESIDENT, WHAT WOULD YOU AND MRS FORD DO AND WHERE YOU FIND ANSWERS IF YOUR SON JACK BROKE HIS NECK IN ONE OF THE MANY SPORTS HE PARTICIPATES IN? THE ANSWERS ARE THERE IF WE WOULD ONLY GO AFTER THEM - WOULD YOU PLEASE HELP US NOW. SINCERELY

LYLE G TAYLOR
15515 52ND AVE WEST
EDMONDS WA 98020

02:31 EST

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AMARILLO DAILY NEWS

34

VOL. 69, NO. 137

AMARILLO, TEXAS, MONDAY, APRIL 12, 1976

24 PAGES PRICE 15c

President's Vow Buoy's Kelly Forehand Family

By RICHARD HAMM
Globe-News Staff Writer

Kelly Forehand shook hands with the President of the United State Saturday night. Asked the chief executive a question and sat back basking in the promise he feels was contained in the ensuing answer

Kelly is paralyzed from the chest down. A jarring, head-on tackle during a 1974 Canyon High School football game has left him confined to a wheelchair. He is able to use his arms,

however his hands and legs refuse to perform their normal functions.

Kelly's doctors told him from the outset he will be paralyzed for the remainder of his life. He refuses to accept that doomsday prediction and the question he put to President Gerald R. Ford at the West Texas State University Field House Saturday was aimed at doing something about it.

"I asked President Ford if he was aware of the need for additional funding for research into the cure of spinal cord injuries," Kelly said yesterday, paraphrasing his actual question.

"I was so scared I really didn't hear his answer at the time," he said adding that his mother and father who shared front row seats with their son wasted no time letting him know Ford's response was "promising."

"The President said he would back it (research) in any way that he could, at least that's how I interpreted it," Kelly said.

Mrs. Forehand was more emphatic. "He said he would be 100 per cent behind any program... that will aid in the cure of spinal cord injuries," she said over the telephone yesterday.

Ford's statement was music to the Forehands' ears. The family has recently become active in an organization "Help Them Walk Again", a charitable foundation formed by the National Paraplegia Foundation.

Following Ford's Canyon appearance they contacted Frank Leonard, a retired FBI agent living in Portland, Ore., who serves as head of HTWA. Leonard also has a son who is paralyzed and was instrumental in obtaining front row seats for Kelly and his parents Saturday.

An excited Frank telephoned the Globe-News yesterday to say Kelly's question and Ford's response represents the first time HTWA has been able to get its message delivered to the president.

He said numerous communications outlining the need for more federal research dollars into spinal cord injuries have been forwarded to the White House only to be shortstopped before reaching the President's desk.

"Kelly's question could very well be the first time the President has heard of this need," Frank said. "It represents a breakthrough and it happened right there in Canyon. I just can't tell you how much this means."

Frank, who took his son to Leningrad, Russia, for treatment of his spinal injury, says leading neuroscientists in this country have told him paralysis from bruised and/or severed spinal cord injuries can actually be cured.

Frank said yesterday from his Portland home that Kelly's informing the President of the need for federal funding of research in this area has been the objective of the organization he heads since its inception.

In a newsletter published by HTWA federal spending on research related to regeneration of the central nervous system is estimated at \$4 million annually. The newsletter points out \$850 million dollars is being spent on cancer research.

Frank said HTWA's financial goal has been set at \$50 million dollars annually over a five-year period. He said the organization hopes to raise approximately \$19 million through a nationwide telathon later this year.

"I'm positive we can help untold numbers of paralysis victims if we can only obtain the funding necessary to conduct the research," he said.

"That's why Kelly's contact with the President is so special," he said. "At least we now know the President is aware of the need."

Mrs. Forehand said she and her husband helped Kelly prepare his question for Ford in advance.

"We approached it from the angle 'If we could only get the President aware of it,'" she said. "You know they filter out so many things before they even get to him (Ford)."

Mrs. Forehand said Ford also acknowledged research being done in foreign countries in the area of spinal cord injuries is ahead of the work currently being done in this country.

"We were mainly trying to draw attention to the fact that this research is underway," she said. "It represents the breakthrough we're waiting on."

As for Kelly, he plans to walk again—with or without the aid of the government.

AMARILLO, TEXAS

APRIL 12, 1976

PRESIDENT FORD ✓
PROMISES 100% SUPPORT
FOR SPINAL CORD INJURY
RESEARCH TOWARD CURE
OF PARALYSIS.

EXHIBIT # 11

RACE DRIVER
BOB HURT
JUST RETURNED
FROM RUSSIA -
HASN'T GIVEN
UP AFTER
7 YEARS -
WHY MUST U.S.
CITIZENS SEEK
HELP OUTSIDE
THIS GREAT LAND
OF OURS ?

Injured Hurt

Not Giving Up SEATTLE P.I. MAY 26

DAYTONA BEACH, Fla. — (AP) —

"They told me to stand up and I thought, 'My God, I haven't stood up in seven years,'" former race driver Bob Hurt said in recalling the highlight of a recent trip to the Soviet Union.

"But I tried, and I did. I didn't want to sit down again. I was enjoying it so much. It was quite a thrill, a thrilling moment," Hurt said.

Before that brief triumph, Hurt hadn't been on his feet since a practice run for the 1969 Indianapolis 500 ended the career of the 29-year-old "comer" in United States Auto Club competition.

His car met the wall at the speedway's first turn in a terrible crash. Hurt's spine was crushed, his spinal cord severely bruised and bashed.

"I've never accepted this injury," Hurt said in a telephone interview from his Daytona Beach apartment. "I've never said I'm going to have to live with it. I'm still looking for a remedy, if that's the word, to what I consider a temporary situation."

That attitude took Hurt to Leningrad and the highly regarded Polenov surgical institute — following more than a dozen meetings and 18 months of negotiations with the Soviet Embassy in Washington.

"The treatment and therapy I received there for six weeks was very beneficial," Hurt said. "They injected drugs into the spinal cord and put me in a high pressure chamber developed in the Soviet space program. They found it had definite effects on the nervous system, and it seemed to work very well."

But at the end of the therapy came disappointment. Scheduled surgery was postponed when doctors found a fusion of Hurt's bones in a position making surgery very dangerous.

"I was pretty down in the dumps for a while," Hurt said. "But if the fusion keeps moving, surgery may be a possibility in six or eight months."

"The doctors seemed optimistic that I might have some movement from my legs after that."

Hurt returned to Daytona, his home for the last two years after moving from Toronto in search of a warmer climate. He went to work securing the material needed to continue his exercise therapy. He also has the blueprints for the type of knee braces and walker he needs for his standing.

"Trying to lick this thing has taken a lot of my time, but I still follow racing," Hurt said. "I raced for 15 years of my life and would love to some day return to it in some form — maybe the technical end or with the media."

"It's been a long struggle for me, and I have a way to go. But the doctors in Russia were surprised and kind of amazed at my strength and incentive. I have a lot of confidence."

Memorandum from

WILLIAM J. VANDEN HEUVEL

June 7, 1976

To: Steve Stark

George Palmer is counsel to the N.Y.S. Election Commission. He is one of the ablest political figures in the state. He also is a leader who saw the possibilities of Governor Carter's candidacy months ago.

If you think his idea has merit, please communicate with him directly. Certainly the idea of scheduling appearances that have compassionate identifications is a good one.

Best

Bill

cc Mr. Palmer

GEORGE V. PALMER
ATTORNEY AT LAW
781 STATE STREET
SCHENECTADY, NEW YORK 12307
EXPRESS 3-3688 (AREA CODE 518)

255

June 2, 1976

William vanden Heuvel, Esq.
61 Broadway
New York, New York 10006

Dear Bill,

One of the problems which Carter faces in reaching a large segment of the electorate is the fact that he does not come through as a compassionate or particularly humane person. He has already demonstrated his independence of the Washington establishment and has incurred the confidence of the public to a very great degree, indeed, through his demonstrated personal integrity.

However, I do think that it would be desirable to take positions on some issues which show true compassion and understanding.

One area in which he might have his staff do some skillful research is the area of mental illness and the mentally handicapped.

It is my opinion that there is considerable discrimination both in law and in the administration of the law in regard to civil rights of mentally handicapped people. In some states, the law will permit a mentally handicapped person to register to vote on an absentee application but when it comes time to actually voting the ballot, he is not, by statute, permitted to do so. Obviously a person away or confined for treatment a distance from his home has a meaningless right of registration if it does not also carry the right to have the absentee ballot as well.

We had a very thorough investigation of voting on the part of the mentally handicapped in New York State in the 1974 election aftermath and some very interesting material and insight was gathered.

Our law provides that a person involuntarily committed to a mental institution or a person in whose behalf a committee of incompetency has been appointed to manage his affairs, may not enjoy the suffrage. Only a small percentage of the people in mental institutions have been committed involuntarily and therefore, they are entitled to vote. Yet, the Federal Voting Rights Act prohibits the imposition of a literacy test to ascertain any level of cognition of

affairs and understanding of public issues through reading, etc. We learned that among those who are not judicially committed or judicially declared incompetent there is a vast range of mental capability and that many persons who are considered to be suffering from mental limitations are not really so limited as one might think and that in fact they are being restricted in the exercise of their franchise by unfair laws or administrative rules.

The mentally handicapped, in most cases, are apathetic and therefore never assert their rights. Furthermore, many of them have serious physical limitations associated with their mental difficulties, thereby limiting their activity in another direction. If Carter could show true compassion for this group of people, a group which is not capable of militant action in its own defense, I think he might break the ice with a lot of people who see him as a person lacking in human compassion.

If your staff would want me to, I would be glad to look into the laws in various states regarding voting rights of persons with mental limitations and develop some legal and factual material for them.

In 1972, when the amnesty issue was a red-hot gut issue which divided a public to a horrible degree, until the summer of 1972 there had been exactly one law review article written in a law review magazine published by a law school university on the subject. This was published in the Law Review of the University at Arizona. Just one article looking at the legal aspects of this emotional issue which had such a disastrous effect on the fortunes of the Democratic party in 1972. I also tried to find law review articles on the questions concerning civil rights and the voting of persons with mental disabilities or limitations. Last year when I attempted to find such materials, I did not find a single article in any of the law journals for the last decade or more, the period during which I made my searches through the indexes.

I know that this letter is very general and somewhat rambling, but if you are interested in the subject matter, I would be glad to develop it further either with you or with an appropriate representative of the Carter committee.

Very sincerely yours,


GEORGE V. PALMER

GVP:ras

P.S. I always wondered how the Federal Government could intervene in this matter to assist mentally handicapped persons in realizing their rights. But if the Federal Government can set standards for voting in federal elections for persons residing overseas, etc., I would think that the Federal Government could set mental competency standards for persons who vote in Federal elections and to say that persons who had these minimal qualifications could not be restricted by more stringent state laws. The states tend to conform their qualifications in specialized situations to the Federal standards once Federal standards are set.

Page 3

That is for voting in local and state elections. Good luck in the final set of primaries next Tuesday.

**JIMMY
CARTER**

**WALTER
MONDALE**



Leaders, for a change.

September 21, 1976

Mr. Paul Marchand
National Association of Retarded Citizens
1522 K St., N.W.
Washington, D.C. 20005

Dear Mr. Marchand:

Governor Carter has released a position paper on Americans with disabilities. I mailed a copy of the paper to you and to Ben Kemper yesterday by air mail special delivery. I hope you will find much useful material in the statement.

Governor Carter believes that we have made an important beginning on the medical, legal, educational, and employment agenda of handicapped and disabled citizens. But in the past eight years of aloofness and uncertainty, that agenda has been ignored and left unfinished. After this period of vetoes, rescissions, inaction, and negative proposals--such as excessive movement toward block grants for human services--it's time for new leadership in Washington.

The Governor supports strong efforts to bring about the day when people in need of residential or institutional care are able to return to the productive mainstream. In addition, he supports strong measures to insure that these facilities are maintained and operated within strict and firm standards, and that these disabled people are cared for with dignity and respect. Further, Governor Carter has pledged to enforce the guidelines laid down for institutional care in the Developmental Disabilities Assistance and Bill of Rights Act of 1975.

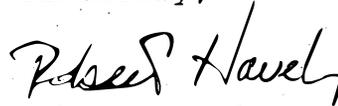
During his term as Governor, Jimmy Carter increased the number of community mental health centers in Georgia from one to eighteen. In 1977, the Georgia General Assembly appropriated \$2.5 million for the expansion of community training centers and group homes. During his term, the number of these facilities increased from 52 to 124. The Governor's emphasis was on de-institutionalization and the restoration of the individual to a comfortable family-style environment.

Governor Carter has pledged to implement the Education of All Handicapped Children Act as swiftly as possible, to insure that all of the children in this nation can receive a high-quality public education. He has emphasized that he believes this to be an important and worthwhile use of our public funds.

One of the most important and central themes in Governor Carter's approach to health care is the urgent need for the prevention of disease and illness. He believes that we must maintain a healthy population in addition to providing health services as such. In particular, he has pledged to provide support for more extensive development of research on the prevention, treatment, and cure of handicapping conditions. During his term, the Governor fought disabling birth defects with extensive programs of pre-natal nutrition and care. He established 44 pilot programs which provided diagnostic services and development and educational programs for young children. Prevention and screening programs were greatly increased.

As Georgia's First Lady, Rosalynn Carter made mental health one of her most important concerns. Both Governor and Mrs. Carter have pledged to take their energy and their commitment to Washington in January.

Sincerely,



Robert Havely
Health Issues Coordinator
National Issues and Policy