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NATIONAL COMMISSION ON MULTIPLE SCLEROSIS ACT

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HEARING

BEFORE THE

SUBCOMMITTEE ON

PUBLIC HEALTH AND ENVIRONMENT

OF THE

COMMITTEE ON

INTERSTATE AND FOREIGN COMMERCE

HOUSE OF REPRESENTATIVES

NINETY-SECOND CONGRESS

SECOND SESSION

ON

H.R. 13978 (and all identical bills)

BILLS ESTABLISHING A COMMISSION TO DEVELOP A REAL-
ISTIC PLAN LEADING TO THE CONQUEST OF MULTIPLE
SCLEROSIS AT THE EARLIEST POSSIBLE DATE

MAY 23, 1972

Serial No. 92-69

Printed for the use of the
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NATIONAL COMMISSION ON MULTIPLE SCLEROSIS ACT

TUESDAY, MAY 23, 1972

HOUSE OF REPRESENTATIVES,
SUBCOMMITTEE ON PUBLIC HEALTH AND ENVIRONMENT,
COMMITTEE ON INTERSTATE AND FOREIGN COMMERCE,
Washington, D.C.

The subcommittee met at 9:30 a.m., pursuant to notice, in room 2218, Rayburn House Office Building, Hon. Paul G. Rogers (chairman) presiding.

Mr. ROGERS. The subcommittee will please be in order.

The hearing this morning is on H.R. 13798, and similar bills pending before the subcommittee relating to multiple sclerosis. H.R. 13798, provides for the establishment of a commission to determine the most productive avenues of research into the possible causes and cures for multiple sclerosis.

Multiple sclerosis is a chronic disease affecting the nervous system. It generally strikes young adults between the ages of 20 and 40 and often leaves its victims crippled and unable to work as the disease runs its course. The average life expectancy of a multiple sclerosis victim is between 13 and 25 years, and in 1967, 1,574 Americans died from this disease.

The cause of MS is still unknown but a number of the characteristics of the disease suggest possible environmental and geographical factors affecting its incidence. Japan for example has a very low incidence of MS while the Shetland and Orkney Islands are stricken at a rate three times higher than any other known population.

The Federal program of research on MS is carried out at the National Institute of Neurological Disease and Stroke and consists of a wide area of basic research to try to determine the cause of MS.

Few studies are being conducted on drugs and other forms of treatment and the cure for MS is still unknown. The purpose of these hearings is to determine the adequacy of Federal programs of research in this area and the feasibility of establishing a commission to direct this research in the most promising areas.

At this point in the record there will be inserted the text of the bills.

(The text of H.R. 13978 and all identical bills follow :)

(1)

- [H.R. 13978, 92d Cong., 2d sess., introduced by Mrs. Heckler of Massachusetts on March 21, 1972;
 H.R. 14258, 92d Cong., 2d sess., introduced by Mr. Jacobs on April 10, 1972;
 H.R. 14449, 92d Cong., 2d sess., introduced by Mrs Heckler of Massachusetts (for herself, Mr. Anderson of Tennessee, Mr. Begich, Mr. Brasco, Mr. Bray, Mr. Boland, Mr. Buchanan, Mr. Don H. Clausen, Mr. Cleveland, Mr. Dulski, Mr. Edmondson, Mr. Edwards of California, Mr. Forsythe, Mr. Griffin, Mr. Gude, Mr. Hamilton, Mr. Hechler of West Virginia, Mr. Helstoski, Mrs. Hicks of Massachusetts, Mr. Kemp, Mr. McFall, Mr. Melcher, Mr. Metcalfe, Mr. Mikva, and Mr. Minish) on April 18, 1972;
 H.R. 14450, 92d Cong., 2d sess., introduced by Mrs. Heckler of Massachusetts (for herself, Mr. Mitchell, Mr. Moorhead, Mr. Podell, Mr. Rangel, Mr. Rosenthal, Mr. Roush, Mr. Roy, Mr. Sarbanes, Mr. Scheuer, Mr. Scott, Mr. Stuckey, Mr. Symington, Mr. Tiernan, Mr. Whalen, Mr. Widnall, Mr. Winn, Mr. Wyatt, Mrs. Abzug, Mr. Madden, Mr. Mazzoli, and Mr. Davis of Georgia) on April 18, 1972;
 H.R. 14559, 92d Cong., 2d sess., introduced by Mr. Ryan on April 20, 1972;
 H.R. 14591, 92d Cong., 2d sess., introduced by Mr. Gallagher on April 25, 1972;
 H.R. 14677, 92d Cong., 2d sess., introduced by Mrs. Heckler of Massachusetts (for herself, Mr. Biester, Mr. Burke of Massachusetts, Mr. Conte, Mr. Drinan, Mr. Donahue, Mr. Galifianakis, Mr. Harrington, Mr. Keith, Mr. Matsunaga, Mr. Morse, Mr. Nelsen, Mr. O'Neill, Mr. Pepper, and Mr. Thompson of New Jersey) on April 27, 1972;
 H.R. 14690, 92d Cong., 2d sess., introduced by Mr. Thompson of New Jersey on April 27, 1972;
 H.R. 14790, 92d Cong., 2d sess., introduced by Mrs. Heckler of Massachusetts (for herself, Mr. Beville, Mr. Edwards of Alabama, Mr. Fraser, Mrs. Dwyer, Mr. Kuykendall, Mr. St Germain, Mr. Brademas, and Mr. Zion) on May 4, 1972;
 H.R. 14951, 92d Cong., 2d sess., introduced by Mrs. Heckler of Massachusetts (for herself, Mr. Archer, Mr. Bell, Mrs. Grasso, Mr. Roe, Mr. Sandman, and Mr. Sisk) on May 11, 1972;
 H.R. 14985, 92d Cong., 2d sess., introduced by Mr. Sikes on May 15, 1972;
 H.R. 15125, 92 Cong., 2d sess., introduced by Mr. Hillis on May 23, 1972; and
 H.R. 15127, 92 Cong., 2d sess., introduced by Mr. Horton on May 23, 1972,
 are identical as follows:]

A BILL

Establishing a commission to develop a realistic plan leading to the conquest of multiple sclerosis at the earliest possible date.

- 1 *Be it enacted by the Senate and House of Representa-*
 2 *tives of the United States of America in Congress assembled,*
 3 That this Act may be cited as the "National Commission on
 4 Multiple Sclerosis Act".

FINDINGS AND PURPOSE

- 6 SEC. 2. (a) The Congress hereby finds and declares—
 7 (1) that multiple sclerosis is a disease characterized
 8 by degeneration within the brain and spinal cord and
 9 by loss of motor and sensory functions;
 10 (2) that this disease, known as the "great crippler"
 11 of young adults", generally makes its first appearance in

1 the very prime of life, between the ages of twenty and
2 forty, already affects great numbers of Americans, and
3 will begin to afflict an even greater number as our young
4 adult population expands;

5 (3) that the cause of multiple sclerosis is unknown
6 and there is neither a preventive nor a cure for the
7 disease; and

8 (4) that the determination of the most effective
9 program for discovering causes, cures, and treatments
10 deserves the highest priority.

11 (b) It is the purpose of this Act to establish a national
12 commission—

13 (1) to determine the most productive avenues of
14 exploration toward researching the possible causes and
15 cures for this disease; and

16 (2) to make specific recommendations concerning
17 the utilization of national resources for that purpose.

18 ESTABLISHMENT OF COMMISSION

19 SEC. 3. There is hereby established a commission to
20 be known as the National Commission on Multiple Sclerosis
21 (hereinafter in this Act referred to as the "Commission").

22 SEC. 4. (a) The Commission shall be composed of
23 eleven members appointed by the President from among
24 individuals with a demonstrated interest in achieving,

1 through research, practical means for preventing or arrest-
2 ing the further progress of multiple sclerosis within the
3 shortest possible time, with a knowledge of the prerequisites
4 for productive research and development, and with a grasp
5 of the forces motivating greater productivity, as follows:

6 (1) six members from the public; and

7 (2) five members from the medical community.

8 (b) The President shall designate one of the members
9 of the Commission to serve as Chairman and one to serve
10 as Vice Chairman.

11 (c) Six members of the Commission shall constitute a
12 quorum, but a lesser number may conduct hearings.

13 (d) Each member of the Commission who is an officer
14 or employee of the United States Government shall serve
15 without additional compensation. Each member of the Com-
16 mission who is not otherwise employed by the United States
17 Government shall receive \$100 per day (including travel-
18 time) during such time as he is actually engaged in the
19 performance of his duties as a member of the Commission.
20 Each member of the Commission shall be allowed travel
21 expenses and a per diem allowance in the same manner as
22 prescribed for persons employed intermittently in the Gov-
23 ernment service under section 5703 (b) of title 5, United
24 States Code.

1 DUTIES OF THE COMMISSION

2 SEC. 5. (a) It shall be the duty of the Commission
3 to make a thorough and complete study and investigation of
4 current research in the field of multiple sclerosis and related
5 neurological diseases to determine the most productive ave-
6 nues of approach toward finding causes, cures, and treatments
7 for multiple sclerosis, including recommendations with respect
8 to the need for enactment of new legislation or the revision of
9 existing legislation. Such study and investigation shall give
10 particular emphasis to funding needs and the means by which
11 the Federal Government can best participate in this effort.

12 (b) The Commission shall transmit to the President and
13 to the Congress a final report not later than one year after
14 the date of enactment of this Act, and shall cease to exist
15 thirty days after submitting its report.

16 SEC. 6. (a) In order to carry out the provisions of this
17 Act, the Commission is authorized to—

- 18 (1) make expenditures;
- 19 (2) hold hearings;
- 20 (3) take testimony orally or by deposition;
- 21 (4) appoint and fix the compensation of such per-
22 sonnel as may be necessary to carry out the provisions
23 of this Act without regard to the provisions of title 5,
24 United States Code, governing appointments in the
25 competitive service, and without regard to the pro-

1 visions of chapter 51 and subchapter III of chapter 53
2 of such title relating to classification and General Sched-
3 ule pay rates; and

4 (5) obtain the services of experts and consultants
5 in accordance with the provisions of section 3109 of
6 title 5, United States Code.

7 (b) Each department, agency, and instrumentality of
8 the executive branch of the Government, including inde-
9 pendent agencies, is authorized and urged to furnish to the
10 Commission, upon the request of the Chairman or Vice
11 Chairman, such information, services, personnel, and fa-
12 cilities as the Commission deems necessary to carry out the
13 provisions of this Act.

Mr. ROGERS. Our first witness this morning is one of our most active members who has made this a special cause of hers. I think it is because of Mrs. Heckler and Ancher Nelsen that this committee has decided to hold these hearings today.

So, we welcome with a great deal of pleasure, our distinguished colleague, Congresswoman Margaret M. Heckler.

**STATEMENT OF HON. MARGARET M. HECKLER, REPRESENTATIVE
IN CONGRESS FROM THE STATE OF MASSACHUSETTS**

Mrs. HECKLER. I thank you very much. My name is Margaret M. Heckler. I represent the 10th Congressional District of Massachusetts.

Mr. Chairman, let me say at the outset, I am very grateful to you to have seen fit to include in your busy calendar a hearing on the multiple sclerosis bill. I feel that your record of legislative accomplishments has been great and is only made greater by today's hearing.

I am also especially grateful to the ranking minority member, Mr. Ancher Nelsen, for the concern he has shown by cosponsorship of the bill, and of course, for the fact he has encouraged this hearing. If you had suggested that this be the Heckler-Nelsen bill, nothing could be more deserving than the Nelsen-Heckler bill, or any other name you might choose to affix to it.

I am joined today by a number of distinguished witnesses, two of whom are young men from my district, Barry Corbett from Attleboro and Robert Baptiste from Mansfield, both members of the Attleboro Jaycees. You will hear from other distinguished witnesses, from the Multiple Sclerosis Society, who offer a depth of human understanding and knowledgeability on the question of MS.

The reason I have become interested, in fact, immersed, in the problem of MS is really due to the inspiration of the Attleboro Jaycees, and particularly to the two individuals who are here today.

They sought me out and asked for my help in an effort to combat this disease. As a matter of fact, they were not asking for a vast Federal empire or the creation of a whole new institute. What they wanted was some Federal recognition of the problem, and the pursuit of the search for an answer with some higher visibility than we have had hitherto.

It seems to me that it is quite appropriate for the House of Representatives and this Congress to take cognizance of the problems of multiple sclerosis. Obviously, the MS Society, one of the greatest voluntary organizations in our community today, has made a valiant effort to take care of the problems of the individuals in their suffering.

Not only have they seen fit to administer collectively to those afflicted with the disease, but they were really in the vanguard of those who were petitioning for the creation of the National Institute of Neurological Diseases and Blindness, now known as the National Institute of Neurological Diseases and Stroke.

Twenty-five years ago, the founder of this organization, who will be with us today and will speak for herself, began that campaign. The Multiple Sclerosis Society has also, I think, found it is in a very unique position, because when Federal funding was not available for multiple sclerosis research, the MS Society volunteered the necessary \$60,000 to conclude research in one area of the problem of multiple sclerosis.

I think today we are also going to hear from our esteemed and distinguished Department of Health, Education, and Welfare. I think it would be entirely remiss and unwise and totally unfair not to recognize the great contributions which this agency of our Government has made in this field.

The competent, dedicated scientists who have worked under HEW auspices have contributed a great deal in the area of exploring the causes and the treatment of MS.

The great support of the National Jaycee Organization, produced by the two young men who are here today whose campaign began in one little town and spread to the State of Massachusetts and to the whole country, the efforts of HEW, the efforts of the great MS Society, all of them, every effort that has culminated in our meeting this morning, all of them have been marvelous.

Yet, I think, we will all quite readily confess they have not been enough. Government as usual, no matter how competent that aspect of government is, is not enough today. Just a few years ago, MS was a little known disease. Obviously, its horizon of awareness has expanded, but it is not a disease which has enjoyed high visibility. The particular sufferers have been engulfed in their personal problems, they have suffered relatively alone. They have received assistance from the particular MS Society in their area, and yet, there has not been any visible or national focus upon their particular problem.

I think that the time has come to remove the dark shadows, and bring the problem out into the open. The problem today is that MS, despite its long history, is still not preventable, and it is still not curable. But it offers one unique hope, and that is that sophisticated scientists have said it is very conducive to a concerted research effort.

As you have mentioned, Mr. Chairman, the MS problem does confront a target group of particularly valuable individuals in our society, those between 20 and 40 years of age. When the victim is a young man who has just finished his college education, beginning his career, it strikes at a particularly tragic point.

When it is a young woman who has started a new family, then the loss not only to herself, but to those around her is great indeed; 500,000 sufferers exist that have been identified with MS, but if one were to include the families, the secondary victims, the numbers would be in the millions.

It is all of these people who have prompted our action today. The fact of the matter is that in the beginning of the search for a way to bring about the coalescing of research efforts throughout the country, it was decided that I would introduce a piece of legislation which you have before you, and that the MS Society and the Jaycees would then rally behind this and would win the support of others in the Congress.

Well, frankly speaking, their rallying has been so effective that 76 Members of our body, within just 6 weeks, have cosponsored this legislation, indicating the need is recognized.

As a matter of fact, we are not seeking any special level of funding, or, indeed, funding at all. It is delightful to see another cosponsor, Mr. Symington, joining us this morning. We certainly appreciate his support on the bill as well.

What we are trying to do through the creation of this 11-man Presidential Commission is to focus on the research into multiple sclerosis.

While the Federal Government has been doing research, the MS Society has privately funded over 70 research grants. Some of it is being pursued in other parts of the world, Australia, Great Britain, Japan, Germany, many other countries. At this point, it would be wise to survey what has been done to coordinate the public and private research, to pinpoint what effort would bear the most promise of a breakthrough and to recommend to the Congress any necessary legislation.

This national spotlight that has begun to focus on MS offers great hope, and really is a potential for enormous breakthrough and enormous change. But I would rely much more than on the spotlight, I would rely on the words of Jonas Salk, whom we remember certainly for his work in terms of the dreaded polio scourge which afflicted our country not too long ago.

Dr. Salk is vitally interested in multiple sclerosis. He has said that there is a time for every disease, and the time for multiple sclerosis is now.

Rather than to pursue funding on a grand scale and scatter our research in ever greater direction, through the mechanism of a Presidential Commission we could bring to bear a cataloging and an inventory of public and private effort with the ultimate hope that through this assessment, we could pinpoint that avenue which offers the greatest chance of success.

This visibility would offer hope not merely to the MS sufferers and their families, but really hope to all others that suffer from neurological diseases. Obviously, Mr. Chairman, your committee has an enormous backlog of legislation. You are involved in many issues.

You care deeply, but it seems that the momentum which represents this meeting this morning and the 76 cosponsors of this measure, which frankly is not the total depth of support in the House of Representatives—I have not exhausted my own personal efforts by any means and I feel that there are 76 others who would come along—but rather than do that, I think the time is now for our committee, for our Congress to act.

I would hope that you would see fit, Mr. Chairman and members of the committee, to pursue this in a very meaningful way, and see to it that it is passed into law. Thank you.

Mr. ROGERS. Thank you very much, Mrs. Heckler, for a very fine statement and for your interest and sponsorship of this legislation. Mr. Nelsen?

Mr. NELSEN. Thank you, Mr. Chairman. May I thank my colleague for appearing here today. May I say to the witnesses, who will appear later, that I know of no member who has been more persistent, and pleasingly so, in bringing to the attention of other members the cause that she has so well laid out for us here in her statement.

I also want to call attention: to those who may be concerned, that this committee, this subcommittee, has operated in a bipartisan way, and has closely worked together on many fronts.

We have produced legislation and we have focused attention on many, many problems. May I say that it is wonderful to hear the testimony that Mrs. Heckler has advanced, because often times, you need to focus attention on a particular problem.

Often you may find within a Federal agency some tool that has not been activated to a great degree in the past that certainly could be

put to use. May I say to these two young men that I congratulate them. In these times where there is so much dissention, so much that is unattractive to the eye, they come in with a good cause and they have spent their time furthering it, and I must say that this is encouraging to all of us.

I want to thank them personally for being here as witnesses. Thank you, Mr. Chairman.

Mr. ROGERS. Thank you very much. Mr. Symington?

Mr. SYMINGTON. Thank you, Mr. Chairman. As Mrs. Heckler has observed, I am a cosponsor of this legislation. I support it wholeheartedly. Thank you.

Mrs. HECKLER. Thank you so much.

Mr. ROGERS. Thank you very much, Mrs. Heckler.

The following Representatives have submitted statements for the record, and without objection the statements will be placed in the record at this point.

STATEMENT OF HON. B. F. SISK, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF CALIFORNIA

Mr. SISK. Mr. Chairman, I appreciate the opportunity to testify today before the subcommittee on a bill which I have cosponsored and which we believe can lead to development of a plan which might conquer the disease, multiple sclerosis.

You will have much expert testimony before you as these hearings progress about the nature of the disease and what is needed in the way of research to conquer it. I won't go into that in any detail but will briefly say a few words about why I think this legislation is needed and why I joined in sponsoring this bill.

The disease strikes down those who are in the very prime of life. It hits those between 20 and 40 years of age, young adults who have left their homes and for the most part completed their education and are just becoming productive members of our society. Thus their loss to society is a national loss and we as national leaders must look to see if we can devise legislation which would authorize projects for furthering research on a national basis which may find a cure or otherwise ameliorate its effects on the sufferer and his family.

There is some evidence of research breakthroughs, however, this research has been scattered. Our bill setting up a national commission would pull some of these research efforts together for a concerted attack on the illness.

It would be the duty of the commission to make a thorough and complete study and investigation of current research in the field of multiple sclerosis and related neurological diseases. The commission would try to find the most productive avenues of approach toward finding causes, cures, and treatments including recommendations for the enactment of new legislation or amending of existing legislation. The commission would report to the President not later than a year after the enactment of this act.

The National Junior Chamber of Commerce and its chapters throughout the United States have been active in carrying the campaign to make the disastrous nature of the disease known to the American public. I think they have succeeded, and now it is our turn to get behind their drive with the necessary legislation to pull all of these efforts together.

I hope Congress as a result of these hearings will join the team composed of the National Multiple Sclerosis Society and the Jaycees.

I know the committee will give this bill its serious and studied consideration. The fact that this bill now has 77 sponsors from all parts of the country indicates that both the disease and the concern for an approach to finding a solution to it are nationwide.

Therefore, I think the establishment of a national commission is entirely appropriate and urge the committee to report out this bill which would accomplish that objective.

Thank you, Mr. Chairman.

**STATEMENT OF HON. FRANK THOMPSON, JR., A REPRESENTATIVE
IN CONGRESS FROM THE STATE OF NEW JERSEY**

Mr. THOMPSON. Mr. Chairman, I would like to take this opportunity to thank the subcommittee for permitting me to testify in behalf of H.R. 13978.

Multiple sclerosis is a chronic and often progressive disease of the brain and spinal cord that usually strikes young adults between the ages of 20 and 40. There is no known cause or cure. It is a disease which not only destroys some of the most productive members of our society, but usually inflicts great psychological damages on the young families involved. There are an estimated half million cases of multiple sclerosis or related neurological diseases in the United States today.

There is growing support for legislation which would provide a realistic plan for dealing with multiple sclerosis. The U.S. Jaycees, the U.S. National Student Association, and Circle K International are among the groups urging their Congressmen to support H.R. 13978. H.R. 13978 would establish a National Commission on Multiple Sclerosis which would be charged with the responsibility of making an up-to-date and thorough study of current research with the hope of identifying the most productive avenues of approach toward finding causes, cures, and treatments. The Commission would be required to report back to the President and the Congress concerning the need for enactment of new legislation or the revision of existing statutes with particular emphasis on funding needs and the means by which the Federal Government could best participate in this effort.

I wholeheartedly urge the subcommittee to act favorably on this legislation in the interests of those afflicted by multiple sclerosis, and in the interests of future generations.

Thank you.

**STATEMENT OF HON. JAMES A. BURKE, A REPRESENTATIVE IN
CONGRESS FROM THE STATE OF MASSACHUSETTS**

Mr. BURKE. Mr. Chairman, I appreciate the time you have given me today to testify in behalf of legislation I have cosponsored, to establish a Commission for the development of a realistic plan leading to the conquest of multiple sclerosis at the earliest possible date. Before I begin my testimony today, I would like to commend the efforts of my

colleague from Massachusetts, Congresswoman Heckler, for identifying the critical need for Federal legislation in this area at the present time.

As Congresswoman Heckler has pointed out, this "is not a billion dollar institute, nor is it intended to be a vehicle for unlimited Government spending." Rather, by creating this Commission we hope to tie together current research and provide a direction for future research to counter this dread disease. I can think of nothing more tragic than the MS victim. A disease which characteristically takes its toll from those between the ages of 20 and 40, it is a long-term disease, affecting the victim for a lifetime, and is progressively debilitating. No known cure or cause exists. However, recent discoveries of those involved in MS research should be a clear indication that now is the time to begin our coordination efforts, to locate and identify what progress has been made to date. When this has been accomplished, the Commission will be able to determine how best to tackle the MS problem on the Federal level. The Commission study should be able to tell us whether our present laws in this area should be revised, or perhaps that new legislation will be needed altogether. Whatever the case, it will give us in Congress a sound basis upon which to enact meaningful legislation in this area, and the MS victim new hope that his tragic situation has not fallen on deaf ears.

Before closing my testimony in support of this legislation to examine all avenues open to research a cure for the disabling disease of multiple sclerosis, I want to call the committee's attention to one of the many grassroot organizations across the Nation that help multiple sclerosis sufferers—organizations I might add, that can offer valuable information to the resulting national bureau that will be established with the enactment of this legislation we are discussing today. The Multiple Sclerosis Service Organization of Massachusetts, Inc., has since its inception stressed two major themes: Friendship and service to the multiple sclerosis patient and his entire family. Their continuing work to monitor programs and legislative proposals to help their members has led the organization to a letter-writing campaign organized by the founder and present executive director of MSSO, Mrs. Jean M. Pantano. The letters emphasize the special set of problems that face women who are disabled with multiple sclerosis—particularly those women who are married and are unable to return to the work force to gain social security coverage. As we know with this disease, often the disabling condition is degenerative and total disability may not occur until after the patient has passed the "recent attachment to the work force" requirement for eligibility for social security disability benefits, that is, under current law an individual is eligible for social security disability insurance benefits only if the person is totally disabled and has worked in social security covered employment for 5 of the 10 years before he became totally disabled.

I mention this legislative proposal to liberalize the eligibility conditions for entitlement to disability insurance benefits, because in addition to long-range proposals to lead to a cure of multiple sclerosis, the immediate needs of persons disabled with this disease must be met and their lives made more livable with social security protection.

**STATEMENT OF HON. JOSEPH G. MINISH, A REPRESENTATIVE IN
CONGRESS FROM THE STATE OF NEW JERSEY**

Mr. MINISH. Mr. Chairman and members of the subcommittee, I am pleased to present this statement in behalf of H.R. 14449, a bill which I have cosponsored with 75 of my colleagues to create a National Commission on Multiple Sclerosis.

Multiple sclerosis is a disease which affects the nervous system of young adults. It strikes nearly all its victims during the prime of life between the ages of 20 and 40. MS is characterized by degeneration within the brain and spinal cord and by a loss of motor and sensory functions.

The legislation pending before your subcommittee would establish an 11-member Commission which would be charged with taking an inventory of all present public and private research activities related to MS. The Commission would then select those with the most promise of achieving a breakthrough and recommend further legislative action that it deems necessary.

We now possess no cure for MS. However, there is reason for hope. Breakthroughs have already been made by members of the research community working in conjunction with the National Multiple Sclerosis Society, other private foundations, and the National Institutes of Health.

Research, however, has been scattered and uncoordinated. Passage of H.R. 14449 would remedy this situation and provide a central body to coordinate and evaluate all research into the cause and the cure for multiple sclerosis.

I respectfully urge the subcommittee to take favorable action on H.R. 14449.

**STATEMENT OF HON. JOHN H. BUCHANAN, JR., A REPRESENTATIVE
IN CONGRESS FROM THE STATE OF ALABAMA**

Mr. BUCHANAN. Mr. Chairman and members of the subcommittee, I appreciate the opportunity to offer a statement to the committee on this legislation.

There are few diseases for which there is no known cause or cure. Cancer is one and the Congress has taken steps to help finance a massive attack on this great killer.

Another disease which threatens the future of many Americans, particularly those between 20 and 40 is multiple sclerosis which affects some 250,000 people in this country annually. Yet another quarter of a million will be stricken by diseases closely related to multiple sclerosis.

At this time there is no known cause or cure nor is there adequate coordinated research being undertaken to find a solution to this disease, which is known as the greatcrippler of young adults.

What is needed, therefore is a concerted effort, a unified effort to find a cause and treatment for multiple sclerosis.

H.R. 13978, the National Commission on Multiple Sclerosis Act would, in my judgment, place very greatly needed emphasis on this too-long neglected disease.

Research into multiple sclerosis is currently being conducted in a number of different and unrelated areas but, unfortunately, nothing

has been done to coordinate these efforts and this is where the Congress can play a vital role. We can create a national emphasis on a search for a treatment of multiple sclerosis. This, Mr. Chairman, is what the National Commission on Multiple Sclerosis would do. It would also, following the completion of a study into the current research in this area, make recommendations on the need for enactment of new legislation or revisions of currently existing legislation.

This measure does not require vast expenditures of money, but it is greatly needed at this time and I respectfully request the committee's favorable consideration of this legislation.

STATEMENT OF HON. JACK EDWARDS, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF ALABAMA

Mr. EDWARDS. Mr. Chairman, members of the committee: I am here to urge your favorable consideration of H.R. 13978, of which I am a cosponsor. This bill will establish a commission to develop a realistic plan leading to the conquest of multiple sclerosis.

This disease is one of the cruelest, most unpredictable known to man. It is a progressively crippling disease which generally strikes persons between the ages of 20 and 40. To date science has not been able to discover where this disease lurks or to find its causes. No cure or effective treatment has been found.

Some of my constituents have, through their personal experiences, acquainted me very eloquently and forcefully with the immeasurable misery and heartache which results when this dread disease strikes a person in the prime of his or her life.

For these reasons, I strongly urge this committee to take affirmative action on H.R. 13978.

STATEMENT OF HON. CHARLES H. GRIFFIN, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF MISSISSIPPI

Mr. GRIFFIN. Mr. Chairman, I appreciate this opportunity to express my support for H.R. 13978, which would establish a National Commission on Multiple Sclerosis.

Multiple sclerosis, known as the "greatcrippler of young adults" is a disease affecting both male and female. In the vast majority of cases, the disease strikes its victims in the prime of life, robbing our Nation of creative and productive citizens. The disease lingers and affects its sufferers for a lifetime.

At present, there is no cure for multiple sclerosis, but there is reason for hope. Research efforts into this disease have been scattered, but there is great hope that a concentrated effort could result in the needed breakthrough. I believe it is necessary that such an effort be made to coordinate and evaluate this research in hopes that it might lead to a more speedy breakthrough.

It is the purpose of this proposed National Commission on Multiple Sclerosis to serve as a vehicle for coordination of research into this disease. The Commission would have the responsibility of making a thorough study of current research in hopes of finding causes, cures, and, hopefully, prevention. The Commission would also survey ways in

which the Federal Government might participate in the fight against multiple sclerosis.

Certainly, in terms of costs, this is indeed a small step for the Congress to make. In terms of the hope it can give, it is a giant step. I would hope that the Congress would begin a commitment to the fight against multiple sclerosis with the passage of H.R. 13978.

STATEMENT OF HON. MICHAEL J. HARRINGTON, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF MASSACHUSETTS

Mr. HARRINGTON. Thank you for the opportunity to testify on behalf of H.R. 13978, which establishes a national commission to undertake a 1-year study of research being done on multiple sclerosis and make recommendations to the Congress concerning the best method to go about conquering this dread disease.

Multiple sclerosis is an especially cruel disease because it strikes people in the prime of life. Most people develop multiple sclerosis between the ages of 20 and 40. Between 250,000 and 500,000 people suffer from multiple sclerosis and other neuromuscular diseases so closely related that the only way multiple sclerosis can be differentiated from these other illnesses is after death. Two million people come from families in which a member has multiple sclerosis.

This disease does not kill—it debilitates. It is marked by a chronic and worsening loss of control and deterioration of the muscular system. Its victims become helpless, looking forward to 85 percent of a normal lifespan spent in pain and suffering.

Research is now being done on multiple sclerosis. But it is fragmented. There is no overall approach, no continuity of research. I am a cosponsor of H.R. 13978, establishing the commission which will take an overall look at the entire research effort now being done. It will not undertake any basic research of its own. But its role is extremely important. After 1 year, it will be able to recommend a program for conquering this disease—a plan which will most effectively utilize the funds and resources available for the fight.

It is estimated that the cost for the Commission's activities over the year will be \$100,000. Each day in Southeast Asia we drop bombs costing 200 times what this Commission's work for an entire year will cost.

The time has come for us to reorder our priorities. We in Congress can help conquer this terrible disease by setting up this Commission to aid scientists now working full time on multiple sclerosis research. We must act quickly to do so.

STATEMENT OF HON. LOUISE DAY HICKS, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF MASSACHUSETTS

Mrs. HICKS. Mr. Chairman, as a cosponsor of H.R. 13978, it is a pleasure for me to come before you today to express my strong support for this bill, which would establish a National Commission on Multiple Sclerosis.

As we are all aware, approximately 500,000 Americans are afflicted with the tremors, muscle weakness, and other symptoms of this insidious disease and related diseases. The symptoms of multiple sclerosis usually begin in the affected person in young adulthood causing varying degrees of disability which may progress on and off over a period of years to the point where he is totally disabled.

The cause of multiple sclerosis is presently unknown. Various theories have been advanced over the years, such as changes in the utilization of food in the body, a lack of certain elements in the diet, climate, viruses, and allergies. At present, researchers are concentrating on two of these theories, viruses and allergies. There is evidence to suggest that slow-acting viruses may infect individuals who get the disease many years before they develop symptoms, perhaps before they are 15 years of age. Other evidence suggests that the body may somehow develop an immunity to some of its own protein which results in the deterioration of some of the cells surrounding nerve tissue. It may also turn out that both of these theories are essentially correct in that viruses may cause the autoimmune reactions of the body.

Although scientists now have a number of clues to work from, far more research will be required before the cause of multiple sclerosis is known and an effective treatment devised. Of course, ultimately we hope that multiple sclerosis can be prevented since preventive medicine is by far the most efficient and effective form of disease control.

The proposed National Commission on Multiple Sclerosis Act would establish a Commission to explore current medical concepts with regard to multiple sclerosis and to determine how best research can move toward learning the cause and cure of multiple sclerosis. The goal of the Commission will be to develop and present recommendations on the best means by which our national resources can be mobilized to conquer this disease. The Commission would provide an opportunity to develop an overview of progress to date in our understanding of this disease. This overview should lead to clearer understanding of what remains to be done both in research and in clinical applications of this research to aid the victims of multiple sclerosis.

We must do all we can to encourage the conquest of multiple sclerosis, which has been referred to as "the commonest disease of the nervous system affecting men and women in the prime of life in northern Europe and North America".

I am proud to be a cosponsor of this important legislation to aid the unfortunate victims of multiple sclerosis and I urge the committee to continue its excellent work in promoting the understanding of the many diseases that afflict mankind by considering this bill favorably.

Mr. ROGERS. Our next witness is Hon. Richard L. Seggel, Deputy Assistant Secretary for Health Policy Implementation, Office of the Assistant Secretary for Health and Scientific Affairs, Department of Health, Education, and Welfare, accompanied by Dr. Edward F. MacNichol, Jr., Director of National Institute of Neurological Diseases and Stroke, NIH, HEW.

We welcome you this morning. We will be pleased to receive your testimony.

STATEMENT OF RICHARD L. SEGCEL, DEPUTY ASSISTANT SECRETARY FOR HEALTH POLICY IMPLEMENTATION, OFFICE OF THE ASSISTANT SECRETARY FOR HEALTH AND SCIENTIFIC AFFAIRS, DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE, ACCOMPANIED BY DR. EDWARD F. MacNICHOL, JR., DIRECTOR, NATIONAL INSTITUTE OF NEUROLOGICAL DISEASE AND STROKE, NATIONAL INSTITUTES OF HEALTH; AND DALE SOPPER, HEALTH LEGISLATIVE ANALYST, OFFICE OF DEPUTY ASSISTANT SECRETARY FOR LEGISLATION, DHEW

Mr. SEGCEL. Thank you, Mr. Chairman and members of the subcommittee. It is a pleasure for me to be here today to present the views of the administration on a legislative proposal to establish a National Commission on Multiple Sclerosis. Your great interest, Mr. Chairman, as well as that of the members of the subcommittee, in the health of the American people is to be commended and we appreciate the opportunity to share with you our plans for dealing with one of the Nation's very serious health problems.

The legislation you are considering today, H.R. 13978, would establish a National Commission on Multiple Sclerosis "to develop a realistic plan leading to the conquest of multiple sclerosis at the earliest possible date." The 11 members of the Multiple Sclerosis Commission would be appointed by the President, with six to be representatives of the public and five from the medical community. The Commission would be authorized to make recommendations for new legislation to implement its multiple sclerosis research plan, with particular emphasis on funding needs. One year after enactment of the legislation, the Commission would report to the President on progress in multiple sclerosis research and treatment.

SCLEROSING DISORDERS

Before discussing the specific proposal for establishing a National Commission on Multiple Sclerosis, Mr. Chairman, I would like to briefly describe for you the scope of the problem presented by the sclerosing disorders and our current research programs in this area.

Multiple sclerosis (MS), is a neurological disease of the 20 to 40 age group for which no effective treatment is available. An estimated 250,000 Americans may be afflicted by this disease, and many more by other chronic degenerative diseases of the nervous system such as amyotrophic lateral sclerosis (ALS), spinal muscular atrophy, and allergic encephalitis. The solution of multiple sclerosis presents a most challenging medical problem since it dooms young adults at the beginning of career and family commitments to many years of increasing disability followed by death.

The disease is a disorder of nervous tissue characterized by the presence of many tiny sclerotic, hardened, areas or plaques scattered diffusely throughout the fiber tracts in the white matter of the brain

and spinal cord. In multiple sclerosis, the most striking pathological change in the central nervous system is destruction of myelin, the material which insulates nerve fibers much as a rubber sheath insulates electric wires. Loss of this nerve fiber insulation along the affected fibers decreases their ability to conduct impulses, thus producing the crippling symptoms of the disease.

In another serious neurological disease of many people, amyotrophic lateral sclerosis, rapidly progressive muscle weakness is due to degeneration of motor cells in the spinal cord and brain which normally activate and control the muscles. The incidence of ALS appears to be nearly the same as that of multiple sclerosis, although its prevalence is much lower because this disease proves fatal in most cases within 2 to 3 years.

The sclerosing disorders, especially multiple sclerosis, subject many families to an emotional stress common to many other diseases as well as economic hardship. Multiple sclerosis attacks and debilitates a very productive age group of our society. It afflicts young mothers and fathers, people finishing long years of education, raising young children, and entering the most productive period of their lives.

THE RESEARCH PROGRAM

A major reason for the establishment of the National Institute of Neurological Diseases and Stroke in 1950 was to focus a national research effort on the problem of multiple sclerosis. Indeed, the National Multiple Sclerosis Society probably played the largest role of any organization in support of the bill which created the Institute. Since its establishment, the Institute has substantially expanded its program of multiple sclerosis research. In 1951, the NINDS funded three projects in multiple sclerosis for a total of \$70,050; by 1972 the research effort had increased to 95 projects totaling \$4,130,000. Of these projects, 65 are extramural grants and 31 are NINDS intramural research projects conducted in Bethesda.

The causes of multiple sclerosis are still unknown, and there is much basic research yet to be done. Investigators are still looking for the essential clue which will lead to the cause and hopefully the cure of the disease.

In its search for the answer to the riddle of multiple sclerosis, the Institute has been following four main research approaches. Because the disease is known to be mainly one of the temperate zone, the answer to the disease is being sought in some factor in the environment. A growing number of epidemiological studies are being conducted among various population groups with known or suspected high or low rates of the disease.

Clues to the solution of many diseases have been found through some factor in the blood, or through recognition of major changes in the structure of the cells and tissues. Therefore, a major research effort is being directed at understanding the biochemistry of multiple sclerosis.

Most recently, great attention has been drawn to the study of viruses as a possible cause of multiple sclerosis. The search for a viral agent is closely related to what could be considered still another research approach, the study of multiple sclerosis as an autoimmune disease in

which the system that protects the body against infection becomes sensitized, with the result that the body destroys its own brain tissues.

In an effort to coordinate basic and clinical research more closely, the Institute is now beginning to develop multiple sclerosis clinical research centers. The first such center is the Reed Neurological Center at UCLA. The main purpose of this center is to provide a facility for conducting clinical studies, for laboratory analysis of blood and tissues for infectious agents, and altered metabolic and immunologic states, for determining possible causes and predicting outcome. However, there is some concern that there may not be enough leads coming from basic research, on which to build a sound clinical research program of this magnitude.

CONCLUSION

Although the NINDS and the National Multiple Sclerosis Society have been supporting and conducting research on multiple sclerosis for more than 20 years, and a great deal is known about multiple sclerosis, it is still a disease that is not fully understood. What can be done to step up the pace of research? Are new initiatives needed?

New research ideas and their translation into proposals for new research programs are the most critical needs, and it is imperative that more basic research be conducted in areas that appear promising. For example, additional attention should be given to the reaction of the brain to infections and the autoimmune response.

The central purpose of H.R. 13978 would be to focus increased public attention on multiple sclerosis research through the mechanism of a highly visible National Commission. While the Department is in accord with the goal of encouraging this research, a National Commission is not necessary. The Commission would necessarily rely upon the same investigators whose opinions are now already available to those administering Government and private research programs in multiple sclerosis. Furthermore, this Department is convinced that investigators are now pursuing the most promising and fruitful research approaches and that a National Commission could do little to accelerate the substance of scientific progress in the sclerosing diseases. Progress will come through the research of scientists. For example, research on viruses has been spurred by the discovery that four neurological diseases of previously unknown origin have been shown to be transmissible by infection. In two of these diseases, viruses have been isolated and identified.

Moreover, the NINDS already has an Advisory Council authorized by the Public Health Service Act, which performs many of the functions of the proposed National Commission. In its review of grant applications, this Council must perform an assessment of the national multiple sclerosis research program and is required to offer scientific advice to the NINDS Director on productive avenues of research.

The National Institutes of Health is presently supporting a substantial research effort related to multiple sclerosis, both in its laboratories and clinics in Bethesda and at numerous medical centers throughout the country. We believe that research projects in multiple sclerosis are currently being given a priority consistent with the magnitude of present research opportunities. We therefore recommend that H.R. 13978 not be enacted.

Mr. ROGERS. Thank you very much. I might say that we have five more witnesses that we have to finish by 10:30 if possible. Mr. Nelsen?

Mr. NELSEN. I notice on page 6, you refer to the Advisory Council, authorized by the Public Health Services Act, which now performs many of the functions of the proposed National Commission. Now, my question is, in the event the Commission is not set up, could the Advisory Council's functions be enlarged so as to give more attention to the problem that we are talking about?

I think the thing that we are concerned about is the focusing of attention and accelerating the activity in hopes of finding a cure for the disease; and in the event that we don't pass the bill, is there something we can do under present authority?

Mr. SEGCEL. Mr. Nelsen, the Advisory Council, of course, is charged with looking at the total program in the Institute and giving advice on the balance of the program. Of course, budget constraints are also involved in these matters. But, in the case of multiple sclerosis, my statement brings out the main problem here is to take advantage of whatever research opportunities we have, and they are not very great at this point.

In other words, we need a lot more basic research. This Council is in a position to make broad judgment, and certainly I can ask the Director of the Institute, Dr. MacNichol, to speak to this. Maybe he would like to enlarge on my answer.

Dr. MACNICHOL. For a long time, the Council was primarily spending its time on reviewing grant applications. Very little time was spent on advising the Institute in regard to policy. Over the past few years, there has been a very considerable shift in this function.

The research and training subcommittees now get most of the routine review over prior to Council meetings. Consequently, the Council has been acting more and more as a planning and an advisory group on what the Institute ought to be doing in certain disease areas.

For example, they have gone over the stroke and spinal cord injury problem rather thoroughly, and have made an extensive report on human communications and its disorders. I am sure with the emphasis and interest that is being shown here, they would be delighted to make a thorough review of MS and recommend a course of future action. The Institute recently set up a commission to investigate the problem of stroke and research opportunities in this field. It could do the same for MS.

Mr. NELSEN. I do not want to leave the impression that I am deserting the bill. I am not. I am going to stay with it. But, we also look for other possibilities in the event the bill fails. I thank the gentleman for his statement. I will withhold any further questions in the interest of time.

Mr. ROGERS. Mr. Symington?

Mr. SYMINGTON. Thank you, Mr. Chairman. The NINDS has many diseases under its purview, does it not?

Dr. MACNICHOL. That is correct.

Mr. SYMINGTON. About how many?

Dr. MACNICHOL. All diseases of the nervous system and of human communications are the Institute's responsibility. This involves several hundreds of diseases, some of which are fortunately quite rare.

Among the most common are stroke, injury to the brain and spinal cord, epilepsy, abnormal development of the nervous system, neuromuscular diseases, Parkinsonism, Huntington's disease and other diseases of movement, the sclerosing disorders including MS, and deafness.

Mr. SEGCEL. We have a table, Mr. Chairman.

Mr. SYMINGTON. It would be helpful if you would submit it for the record. Does that also indicate the sums spent?

Mr. SEGCEL. Yes, the sums of the total budget in each area.

Mr. SYMINGTON. That will be helpful. I think at some times special effort helps.

(The following table was received for the record:)

FISCAL YEAR 1973 PRESIDENT'S BUDGET, NINDS RESEARCH BY DISEASE CATEGORY

(In thousands)

	1971 actual			1972 estimate			1973 President's budget		
	Extramural		Intramural	Extramural		Intramural	Extramural		Intramural
	Num-ber	Amount	Total amount	Num-ber	Amount	Total amount	Num-ber	Amount	Total amount
I. Neurological disorders:									
A. Neurological disorders of early life...	176	6,932	14,496	189	7,590	7,419	172	7,590	15,009
B. Neurological disorders of adult life...	62	2,977	3,302	67	3,260	3,351	60	3,260	3,613
C. Cerebrovascular disorders...	71	5,456	5,784	81	7,974	6,554	73	7,974	8,633
D. Epilepsy...	43	2,173	3,194	46	2,379	2,403	42	2,379	2,782
E. Sclerosing disorders...	57	2,960	3,257	64	3,391	3,739	58	3,391	3,794
F. Muscular disorders...	144	4,787	5,552	165	5,542	6,350	149	5,542	6,353
G. Infectious disorders of nervous system...	11	323	1,528	12	354	1,701	11	354	2,055
H. Accident and injury to nervous system...	57	2,536	3,578	67	5,777	1,325	62	5,777	7,102
J. Tumors of the nervous system...	23	676	1,048	25	740	1,402	23	740	1,405
M. Neuroendocrine studies...	86	2,737	2,766	93	2,997	31	84	2,997	3,028
N. Neural aspects of learning and behavior...	43	1,548	1,965	46	1,695	21	42	1,695	2,145
P. Nervous system studies related to normal functions...	171	5,358	6,323	185	5,867	1,040	168	5,867	6,907
II. Sensory disorders:									
A. Hearing and equilibrium...	146	6,757	6,757	157	7,399	1	142	7,399	7,799
B. Speech and other higher CNS functions...	35	1,648	2,403	37	1,805	1,065	34	1,805	2,870
D. Other sensory disorders...	119	3,768	4,757	128	4,125	1,118	116	4,125	5,243
E. Multicategorical...	14	3,013	3,564	15	3,299	595	14	3,299	3,894
Subtotal...	1,258	53,649	70,274	1,377	64,194	20,043	1,250	64,194	84,237
GRS...		5,027	5,027		5,136	5,136		5,439	5,439
Scientific evaluation and planning...		125	125		130	130		130	130
Fellowships...		2,782	2,782		2,782	2,782		2,782	2,782
Training-extramural...		14,300	14,300		14,300	14,300		14,300	14,300
Research management and program services...		1,929	1,929		2,093	2,093		2,093	2,093
Noncategorical obligations...		2,508	2,508		2,334	2,334		2,365	2,365
Management fund...		6,500	6,500		5,507	5,507		5,588	5,588
Total...	1,258	75,883	103,445	1,377	86,542	29,977	1,250	86,845	117,298

Mr. ROGERS. Mr. Preyer?

Mr. PREYER. I have no questions. I want to thank Mr. Seggel for a statement which I think is both compassionate and also states clearly his position. It is a terrible disease as you point out.

The fact that it strikes the productive period of people's lives, makes it particularly a tragic one. I appreciate your statement.

Mr. ROGERS. How many researchers are working on multiple sclerosis?

Dr. MACNICHOL. I could not answer that exactly. We have about 95 separate projects of which 64 are extramural grants which would have anywhere from two or three workers to 15 or 20, depending on the size—

Mr. ROGERS. Are these doctoral people, or at what level?

Dr. MACNICHOL. Each of the projects has a principal investigator who has a doctor's degree. Most of the others would be support personnel, such as technicians, animal caretakers, secretarial.

Mr. ROGERS. So, you have at least 64 doctoral people working on multiple sclerosis in your extramural. What about intramural?

Dr. MACNICHOL. Intramural, in terms of man-years, it is about 34.

Mr. ROGERS. That is not what I am talking about, man-years. How many people do you have working on multiple sclerosis in your Institute? Five, six, seven?

Dr. MACNICHOL. We have 18 doctoral level investigators working on MS and 16 nondoctoral employees.

Mr. ROGERS. How many are in the administrative staff?

Dr. MACNICHOL. I was not including those because the administrative staff oversees such a variety of programs, and it really is impossible to sort out.

Mr. ROGERS. You are giving us just the ones who are technicians and the doctors?

Dr. MACNICHOL. People who are actually doing research.

Mr. ROGERS. Your total budget is \$4 million?

Dr. MACNICHOL. \$4.1 million.

Mr. ROGERS. How is that divided, interamurally and extramurally?

Mr. SEGSEL. Intramurals run \$745,000 intramural. Extramurals \$3,391,000.

Mr. ROGERS. Is most of that going to this clinic you are talking about?

Dr. MACNICHOL. No; that is only one project. The funding of that is \$379,000 in fiscal year 1972. So, most of it is on individual projects.

Mr. ROGERS. Who is your top man on research, who really handles it for you?

Dr. MACNICHOL. That, I am afraid I cannot give a direct answer to, because we are divided up in such a way that Dr. Goldstein is primarily responsible in the extramural program for our grantees, Dr. Jacob Brody in epidemiology is primarily responsible for the epidemiology studies that we have been making in the field.

Dr. King Engel for the clinical research that is going on in the NIH Clinical Center on multiple sclerosis, and Dr. Carlton Gajdusek, Dr. Clarence Gibbs, and Dr. John Sever for the study of virus diseases affecting the central nervous system of which MS may be one.

Mr. ROGERS. But, you don't have anybody really heading it up and checking what is happening and coordinating it?

Dr. MACNICHOL. The executive staff of the Institute coordinates all of the programs. It meets weekly and consists of the Director, Deputy Director, Associate Directors, Executive Officer, and Information Officer. It plans and coordinates all programs.

Mr. ROGERS. Is there one man responsible for multiple sclerosis?

Dr. MACNICHOL. No, we do not have any one person who is the director or coordinator for multiple sclerosis. The Institute is not set up in that manner.

Mr. ROGERS. I would hope that you would look at your organization. It seems to me that you could get way off on a tangent if you don't have someone who is responsible for coordinating and bringing it together.

Dr. MACNICHOL. This is exactly the function of the executive staff.

Mr. ROGERS. Are all of those people experts on multiple sclerosis, I presume not?

Dr. MACNICHOL. No; since we have to cover a wide variety of diseases. We would not hope to have a separate individual on the executive staff responsible for each. However, when special problems involving a particular disease arise, we invite the experts such as Dr. Brody and Dr. Engel to sit with us.

Mr. ROGERS. I think that the committee will want to look at your organization. I think you might submit for the record all of the research projects, their stages, how long they have been going on, the amount of money, what has been accomplished, and any breakthroughs you see that ought to be exploited. Thank you.

Dr. MACNICHOL. We will be glad to do that.

Mr. ROGERS. Dr. Carter, do you have any questions?

Mr. CARTER. No questions, Mr. Chairman.

Mr. NELSEN. Mr. Chairman, I would like to also suggest that if a structural change would be helpful, we would like to get recommendations along those lines. It may very well be that when you get frozen into a pattern where a change would be helpful and, if so, we would like to know about it.

Mr. ROGERS. I think it would be well to list for us all of the researchers that you have in-house and their training, their degrees and so forth and their efforts. Thank you so much.

Dr. MACNICHOL. Thank you, Mr. Chairman.

(The following information was received for the record:)

MULTIPLE SCLEROSIS

National Institutes of Health, National Institute of Neurological Diseases and Stroke

Multiple sclerosis is the most common demyelinating (loss of fatty sheath surrounding nerve fiber) disease of man. It affects primarily young adults in temperate climates, such as those of North America and Europe. In the United States alone, an estimated 250,000 patients suffer from the disease. Many thousands of others suffer from closely related sclerosing disorders.

NINDS Research Support for Sclerosing Disorders

1969, \$3,163,000.	1972 (estimate), \$4,130,000.
1970, \$2,892,000.	1973 (estimate), \$4,136,000.
1971, \$3,257,000.	

In 1868, Jean-Martin Charcot, a famous French medical scientist, gave the world a description of a strange neurological disease, now known as multiple sclerosis. He described the classical clinical symptoms of the disease: tremor

when movement is attempted, an involuntary movement of the eyes called nystagmus, and hesitations in speech. He later added the characteristic pathologic features of the disease available only at autopsy: demyelination without destruction of axons, accompanied by scarring or hardening (sclerosis).

Multiple sclerosis today is still a mystery disease, as it was a century ago. Neither the cause nor an effective treatment are known.

The natural history of the disease is traced from symptom-free early childhood through a maze of progressive combinations and the treachery of advancing complications. In the benign form, the episodes may be mild and fleeting with years between bouts. In the active form, severe prolonged attacks develop with widespread neurologic disability, which may or may not be followed by brief remissions with incomplete recovery. Severe attacks lead eventually to incapacity after a variable number of years.

In multiple sclerosis, the neurological symptoms of the disease are apparently caused by the patchy destruction of myelin (the fatlike membranes that are wrapped around the central component of the nerve fiber, the axon). This fatty substance can be compared to the rubber in the insulation around a telephone wire. When the myelin sheath surrounding a nerve fiber breaks down, the conduction of impulses along the now exposed fiber is disrupted. Eventually scar tissue forms in the demyelinated areas, producing the sclerotic plaques for which the disease is named.

There is no specific treatment for multiple sclerosis. In a cooperative double-blind controlled study, adrenocorticotrophic hormone (ACTH) was considered to have beneficial effects somewhat superior to placebo. Short-term, high-dosage ACTH treatment appeared to hasten amelioration of symptoms and signs, but there was no evidence that the ultimate extent of improvement was greater than that attained by the placebo.

Physiotherapy has much to offer the disabled patient. Assisted, passive and resisted movements, and walking exercises supervised by trained physiotherapists do much to reduce spasticity, diminish difficulty in walking, and improve the patient's morale. It should be emphasized that the patient must not become exhausted by exercises, and treatment sessions, therefore, should be frequent and short, rather than prolonged.

PROGRAM DEVELOPMENTS

Basic research studies (extramural program)

Because multiple sclerosis is a disorder of unknown etiology (cause), much of the research is still at the test tube or basic level. Investigators are still looking for the essential clue which will lead to the cause and hopefully the cure of the disease.

The NINDS is conducting an active extramural grants program in which it is underwriting many research projects at university medical centers and at a number of private institutions or foundations. These studies are largely concentrating on understanding the fundamental mechanisms of the disease. Typical subjects of such studies are: the chemistry of the myelin sheath, the role of fatty acids in demyelination, the chemistry of brain lipids and protolipids, and immunologic responses in demyelinating diseases. A number of investigators are looking at lymphocytes (cells involved in immunity) and lymphotoxic factors in the blood of multiple sclerosis patients.

In several studies, experimental allergic encephalomyelitis (EAE) is being used as a model disease for multiple sclerosis research. Investigators are inducing EAE in laboratory animals (guinea pigs, rats, monkeys, hamsters, and rabbits) by injections of a basic protein from myelin along with other material that assists in provoking an immune reaction. Knowledge acquired about the mechanisms producing this disease and factors that decrease its severity should be applicable to the conquest of multiple sclerosis.

A large NINDS program grant, "Fundamental Studies Relating to Multiple Sclerosis," is part of the work of the new Reed Neurological Research Center at ULCA. The Center located in a specially designed 8-story building has extensive laboratory facilities, an outpatient service section, and a large number of beds for neurology patients.

The main purpose of the Center is to provide a facility for conducting clinical studies, for accumulating data on the clinical and laboratory manifestations of multiple sclerosis and other neurological diseases, and for determining possible causes and prognostic factors requiring further study. The clinical studies provide material for studies to determine if plasma from multiple sclerosis patients in remission can be used to suppress symptoms during an acute attack in the

same patient, to search for evidence of delayed hypersensitivity to central nervous system tissue in multiple sclerosis patients, and to characterize the demyelinating factor in sera from multiple sclerosis patients.

Serological studies of common viruses in cases of multiple sclerosis and controls are being conducted by the Institute's Section on Infectious Diseases to test the hypothesis that multiple sclerosis may be caused by an unusual response to a common virus infection. Using a battery of common virus antigens, investigators conducted serological analysis by hemagglutination and complement fixation methods. Differences between the patient, his sibling (brother or sister) and unrelated persons used for comparative purposes were analyzed. A portion of frozen serum is being banked to test promising hypotheses in the future.

Slow virus laboratory

The NINDS slow virus laboratory was designed to determine whether infection is a cause of chronic progressive degenerative diseases of the central nervous system of man and animals. In this special facility and under contract in a number of centers, large numbers of primates and small laboratory animals have been inoculated with suspensions of tissues obtained at biopsy or early autopsy from humans and animals affected with neurological and systemic disease. Tissue cultures of brain tissue are maintained for long periods to unmask hidden viruses.

This year two central nervous system diseases—kuru and Jakob-Cruetzfeldt disease—previously transmitted only to chimpanzees were transmitted to three species of New World monkeys, which are cheaper and easier to handle. Both agents have been maintained in brain tissue cultures. Serial passage and viral pathogenesis and characterization studies have been expanded, utilizing the monkeys. During the year, the laboratory received more than 400 specimens from patients with central nervous system diseases. These include over a dozen brain biopsies and early autopsy specimens from patients with multiple sclerosis.

In conjunction with the work of the slow virus laboratory—which has become a world center for such investigations—an elaborate search for antibody to human viruses, using multiple sclerosis sera and cerebrospinal fluid (CSF), has been carried out. The *possible* role of an unusual form of measles virus infection in multiple sclerosis also is under study. In addition to studying diseases in search of viruses, this laboratory is investigating the nature of over 100 virus strains isolated from normal chimpanzee and human tissues, the activation of which may cause generalized diseases. In these studies attempts are made to develop animal or tissue culture models for determining physical, chemical, and biological properties and pathogenesis (origin and development of disease) of these slow-acting viruses.

Epidemiological studies

Epidemiology has probably contributed more in recent years to the understanding of multiple sclerosis than any other discipline of medicine. Although the findings are conflicting, any hypothesis (supposition) concerning etiology must explain the varying prevalence of the disease throughout the world.

New studies of the epidemiology of multiple sclerosis include a survey of 6,000 multiple sclerosis patients among veterans of the Second World War and the Korean War. Patients will be matched with controls to determine geographic patterns, socioeconomic status, urban-rural localization and numerous other variables which have been tested for multiple sclerosis. An extensive investigation of migrant and non-migrant population to and from high and low risk areas for multiple sclerosis will be conducted. Emphasis will be placed on the relationship between any communicable disease experienced in childhood and subsequent multiple sclerosis.

A study supported by the National Multiple Sclerosis Society will determine the prevalence of multiple sclerosis among Vietnamese immigrants to France. Vietnamese, originally from a low-risk section of the world, have been moving to France since at least World War I. An estimated 75,000 now live in Paris and its suburbs. The investigators will try to ascertain if Vietnamese who migrated to France before and after the age of 15 have differing prevalence rates of multiple sclerosis and whether the multiple sclerosis prevalence rate of Vietnamese living in France (a high-risk zone) differs from that of Vietnamese continuing to live in Vietnam (a low-risk area).

Cooperation between NMSS and NINDS

Since the founding of the National Institute of Neurological Diseases and Stroke 22 years ago, the Institute has worked in close cooperation with the National Multiple Sclerosis Society. In fact, the Society was instrumental in

the establishment of the Institute in 1950. Over the years, the two organizations have coordinated their publicity and educational campaigns. Especially important is the way the two organizations complement each other in conducting research programs. The role of the Society as far as the overall objective of multiple sclerosis research has been to provide alternate channels of support for investigators. Such channels protect the investigator against any discrimination or bias that might exist within a single review mechanism.

The cumulative total of research and fellowship grants awarded by the Society since its founding has now reached more than \$16 million. These funds have supported or are supporting more than 1,100 separate awards for research and training. During the past year, the Society has spent more than one and a half million dollars in grant support.

An example of a program of mutual benefit is the establishment of the international center for collection, storage, and distribution of control and multiple sclerosis tissue. This bank at the University of Michigan in Ann Arbor is supported by the Society. From this bank, investigators around the world can draw materials for approved studies.

RESEARCH PROGRESS

There are three main research approaches in the attack on multiple sclerosis. Because the disease is known to be mainly one of the temperate zone, the answer to the disease has long been sought in some factor in the environment. During the past twenty years a growing number of epidemiological studies have been conducted among various population groups with known or suspected high or low rates of the disease.

Another approach is through understanding the biochemistry of the disease.

A third approach to the disease, and recently the most popular one, is the search for a virus or viruses thought to be a possible cause of multiple sclerosis. In the past few years, proof that several neurological diseases can be transmitted to animals has given new impetus to this effort.

The search for a viral agent is closely related to what could be considered still another research approach, the study of multiple sclerosis as an autoimmune disease. If multiple sclerosis is an autoimmune disease (that is, a reversal of the normal immune process in the multiple sclerosis patient's body), it is believed that the autoimmune process might be triggered by a virus in some way.

The Hunt for a Multiple Sclerosis-Related Virus

While there is considerable indirect evidence that multiple sclerosis is caused by an infective agent, most likely a virus, no such agent has yet been identified. This could mean that multiple sclerosis is not a virus-caused disease. This could mean, alternatively, that the presently available techniques are not adequate to detect this particular infectious agent.

In the search for a viral agent, studies follow two general approaches. The first is the study of the effect of various infectious agents on the central nervous system of man and animals, and the delayed neurological effects of infections in childhood and early life. The other focus is the infection of the central nervous system by slow, latent, and temperate viral agents or agents somewhat like viruses but lacking many of the classical characteristics of viruses.

A measure of success with the second approach, the search for slow viruses, has broadened the field of research. It was the discovery that such diseases as kuru and Jakob-Creutzfeldt disease were obviously caused by some as yet undetermined viral agent that has convinced most multiple sclerosis researchers that some other neurological disorders are probably of viral origin.

The results obtained in these long-term slow virus studies have suggested the establishment of a new group of "infectious filterable" diseases which have been classified as subacute spongiform virus encephalopathies. These include kuru and Jakob-Creutzfeldt disease of man, and scrapie and mink encephalopathy of animals. These studies are providing techniques which may have importance in the investigation of the possible infectious nature of multiple sclerosis, amyotrophic lateral sclerosis, Parkinson's disease, and Alzheimer's disease.

Additional proof was gained during the past year that viruses cause neurological diseases in man and animals. It was demonstrated that viral isolates from the brain and lungs of sheep with fatal progressive pneumonia in Montana are antigenically closely related or identical to visna and maedi viruses of Iceland. The discovery of these viruses in the United States for the first time is of considerable interest to investigators. They should be able to use visna, a demyelinating disease of sheep, as a model in the study of demyelinating diseases of man, particularly multiple sclerosis.

Proof that a slow virus can cause neurological disease opened up another possibility. Could multiple sclerosis be an unusual response to a common virus? The belief that a common virus could be involved was greatly strengthened when it was discovered two years ago that subacute sclerosing panencephalitis (SSPE), a fatal disease of children, was caused by a measles virus residing in the body for many years after acute measles infection.

Recently it was discovered that the suppressed measles virus infection observed in SSPE is not limited to the central nervous system. Investigators isolated measles virus in lymph node biopsies from two of five SSPE patients, both with early clinical symptoms, but not in biopsies taken from control subjects. The investigators believe that the presence of latent, intracellular measles virus in the lymph node cells indicates a persistent infection with specific defectiveness of the cellular immunity.

The discovery that one neurological disease is probably caused by the measles virus increased speculation that measles or another common virus could be associated with multiple sclerosis. To determine if such a relationship exists, a number of antibody studies have been conducted. From two such studies, NINDS investigators have found that multiple sclerosis patients do have consistently higher antibody levels against many viruses than controls. This observation points to an infectious or immune mechanism as being involved in the etiology of multiple sclerosis. Higher antibody levels were also found in siblings of multiple sclerosis patients. This finding suggests that the phenomenon may be related to a common familial exposure or a familial immunologic defect.

Further studies are needed to clear up the many questions raised by this research. It is hoped that this kind of study can be repeated in a compact, isolated area where the population is relatively stable and dense and where a given strain of measles virus is more likely to infect all persons in the community at the same time. Such an area is the Orkney and Shetland Islands which have an extremely high prevalence (240 per 100,000) of multiple sclerosis and a well-studied and defined patient population.

Multiple Sclerosis an Autoimmune Disease?

It is now believed by some investigators that an immunological disturbance may produce the nerve tissue damage responsible for the crippling symptoms of multiple sclerosis. It is suspected that some initial stimulus (possibly a virus infection) releases into blood circulation certain components of the central nervous system previously sequestered from the body's immune mechanism. Because of this prior isolation, these nerve tissue components have never been recognized as normal body constituents. Instead, when released in some fashion they are taken to be new and therefore foreign invaders. The immune mechanism thereupon reacts to them as to any invader and produces antibodies. These antibodies now circulate throughout the body and attack the vital nerve tissue containing this component.

The myelin sheath around the nerves of the brain and spinal cord bear the brunt of the damage in patients with multiple sclerosis. An important segment of the research in this disease is based upon the hypothesis that the injury to the myelin sheath is the result of a misdirected attack against the sheath by the patient's own immune system.

For many years, a model for studies of autoimmune disease affecting the brain and spinal cord has been a disease called experimental allergic encephalomyelitis (EAE), which can be produced in laboratory animals. EAE is similar to multiple sclerosis in certain important aspects. For this reason, a number of scientists are attempting to correlate studies of multiple sclerosis with those of EAE in the hope of finding a common factor that will lead to a better understanding of multiple sclerosis.

EAE can be induced by injections of the basic protein, which is found in the myelin that insulates nerve fibers. Basic protein consists of 170 amino acids linked together in a more-or-less longitudinal sequence. It has been found in a number of laboratories that a nine-amino-acid fraction, or peptide, of this molecule is alone capable of inducing the disease in some animal species. Work in other laboratories has shown that a quite different peptide fraction can induce EAE in other species.

The nine-amino-acid peptide has been synthesized, and extensive studies are under way to find out if it can be modified (or used in some manner) so that it is unable to induce EAE, but can, at the same time, arrest the progress of the disease process.

The research is aimed at ultimately developing a safe means to terminate the progression of multiple sclerosis in man, but realization of this objective is some time away.

NATIONAL INSTITUTE OF NEUROLOGICAL DISEASES AND STROKE
CURRENT MULTIPLE SCLEROSIS AND RELATED RESEARCH—RESEARCH GRANTS

Title of project	Principal investigator, institution, location	Supported since	Funds
Chemistry of brain lipids and proteolipids....	Folch-Pi, Jordi, McLean Hospital, Division of Massachusetts General, Belmont, Mass.	1952	\$26, 157
Electron microscopy of the nervous system....	Duncan, Donald, University of Texas Medical Branch Galveston, Galveston, Tex.	1955	33, 093
Factors influencing neuron development and function.	Murray, Margaret R., Columbia University, New York, N.Y.	1955	60, 326
Some aspects of the state of brain cations and fluids.	Katzman, Robert, Yeshiva University, New York, N.Y.	1958	46, 307
Biosynthesis and metabolism of galactolipids.	Burton, Robert M., Washington University St. Louis, Mo.	1958	34, 625
Molecular mechanisms of membrane transport in brain.	Hokin, Lowell E., University of Wisconsin, Madison, Wis.	1958	75, 152
Pathogenesis of CNS and autoimmune disorders.	Good, Robert A., University of Minnesota, Minneapolis, Minneapolis, Minn.	1959	62, 457
The chemistry of cells and cell portions from the CNS.	Norton, William T., Yeshiva University, New York, N.Y.	1959	106, 699
Biosynthesis of lipids in experimental demyelination.	Smith, Marion E., Stanford University, Stanford, Calif.	1960	28, 374
Metabolism and function of complex lipids....	Kennedy, Eugene P., Harvard University, Boston, Mass.	1959	44, 336
Phospholipids of the nervous system.....	Agranoff, Bernard W., University of Michigan, Ann Arbor, Ann Arbor, Mich.	1961	50, 443
Tissue culture of nervous tissue.....	Hild, Walther J., University of Texas Medical Branch Galveston, Galveston, Tex.	1962	40, 903
Experimental allergic encephalomyelitis.....	Alvord, Ellsworth C., Jr., University of Washington, Seattle, Wash.	1960	74, 156
Myelinating process in nerve tissue culture...	Yonezawa, Takeshi, Kyoto Prefectural University of Medicine, Kyoto, Japan.	1960	10, 528
Brain glycolipids—metabolism and pathology.	Radin, Norman S., University of Michigan, Ann Arbor, Ann Arbor, Mich.	1960	120, 318
Protein breakdown in the brain.....	Lajtha, Abel, Research Institute, Neurochem and Addict., New York, N.Y.	1961	29, 058
Biochemistry and histopathology of cycasin toxicity.	Matsumoto, Hiromu, University of Hawaii, Honolulu, Honolulu, Hawaii.	1962	33, 618
Nervous tissue lipid metabolism in demyelination.	Berry, James F., University of Minnesota, Minneapolis, Minneapolis, Minn.	1964	32, 102
Amyotrophic lateral sclerosis in the Kii Peninsula.	Yase, Yoshiro, Wakayama Medical College, Wakayama, Japan.	1965	14, 578
Immunologic responses in demyelinating diseases.	Rauch, Helene C., Stanford University, Stanford, Calif.	1964	57, 379
Study of brain proteins and macromolecular complexes.	Le Baron, Francis N., University of New Mexico, Albuquerque, N. Mex.	1964	15, 818
Cerebral and vitreous humon hyaluronopeptides.	Wardi, Ahmad H., Warren State Hospital, Warren, Pa.	1965	16, 071
Purification of myelin proteins.....	Wolfgram, Frederick J., University of California, Los Angeles, Los Angeles, Calif.	1965	42, 820
Function of the thymus.....	Arnason, Barry G., Massachusetts General Hospital, Boston, Mass.	1966	49, 541
Lipid metabolism in normal and pathological states.	Rouser, George, City of Hope Medical Center, Duarte, Calif.	1966	50, 858
Immune basis of disease—allergic encephalomyelitis.	Paterson, Philip Y., Northwestern University, Chicago, Ill.	1965	88, 549
The chemistry and biochemistry of long-chain bases.	Weiss, Benjamin, New York State Psychiatric Institute, New York, N.Y.	1965	16, 042
Biochemistry of inositol and phosphoinositides.	Hauser, George, McLean Hospital Division of Massachusetts General, Belmont, Mass.	1968	35, 753
Biophysical cytology of cultured neural tissues.	Crain, Stanley M., Yeshiva University, New York, N.Y.	1965	63, 480
Biology of myelinated CNS in tissue culture...	Bornstein, Murray B., Yeshiva University, New York, N.Y.	1966	73, 234
Encephalitogenic nature of altered brain preparation.	Swanborg, Robert H., Wayne State University, Detroit, Mich.	1967	17, 404
Relationship between brain lipids and electrolytes.	Lees, Marjorie B., McLean Hospital Division of Massachusetts General, Belmont, Mass.	1966	68, 971
Phospholipid metabolism and membrane synthesis.	Weinbaum, George, Albert Einstein Medical Center, Philadelphia, Pa.	1968	16, 668
A biochemical genetic study of bacterial lipids.	Berkowitz, David B., University of Pennsylvania, Philadelphia, Pa.	1968	27, 760
Experimental hypertrophic neuropathy.....	Dyck, Peter J., Mayo Foundation, Rochester, Minn.	1967	21, 948
Role of polyunsaturated fatty acids in demyelination.	Bernsohn, Joseph, Northwestern University, Chicago, Ill.	1969	24, 175
Chemistry and function of brain plasmalogens.	Rapport, Maurice, M., New York State Psychiatric Institute, New York, N.Y.	1968	38, 908
Structure, metabolism and function of myelin proteins.	Shapira, Raymond, Emory University, Atlanta, Ga.	1969	75, 065
Myelin biosynthesis and turnover.....	Horrocks, Lloyd A., Ohio State University, Columbus, Ohio.	1969	26, 323
Comparative in vivo and in vitro studies of myelin.	Cravioto, Humberto M., New York University, New York, N.Y.	1968	29, 475

NATIONAL INSTITUTE OF NEUROLOGICAL DISEASES AND STROKE—Continued
CURRENT MULTIPLE SCLEROSIS AND RELATED RESEARCH—RESEARCH GRANTS—Continued

Title of project	Principal investigator, institution, location	Supported since	Funds
Myelin formation and its relation to the neuron.	Kaufman, Bernard, Duke University, Durham, N.C.	1969	\$22, 623
Fundamental studies relating to multiple sclerosis.	Rose, Augustus S., University of California, Los Angeles, Los Angeles, Calif.	1969	864, 157
Demyelinating disease caused by hepatitis virus.	Weiner, Leslie P., Johns Hopkins University, Baltimore, Md.	1969	25, 518
Electronmicroscopy cytopathology of organized CNS and PNS cultures.	Terry, Robert D., Yeshiva University, New York, N.Y.	1969	83, 281
Phospholipids and nerve-muscle function.....	Rosenberg, Philip, University of Connecticut, Storrs, Storrs, Conn.	1970	20, 473
Pathogenesis and etiology of multiple sclerosis.	Adams, John M., University of California, Los Angeles, Los Angeles, Calif.	1970	23, 509
Fine structural pathology of myelin.....	Lampert, Peter W., University of California, San Diego, La Jolla, Calif.	1970	37, 391
Fatty acid elongation in brain.....	Yatsu, Frank M., University of California, San Francisco, San Francisco, Calif.	1970	54, 817
Interactions of phosphoinositides in myelin....	Hendrickson, H. Stewart, St. Olaf College, Northfield, Minn.	1970	14, 195
Physical state and biological activity of phospholipids.	Dennis, Edward, University of California, La Jolla, Calif.	1970	13, 980
Central nervous system membranes and acidic.	Eng, Lawrence F., Veterans Administration Hospital, Palo Alto, Calif.	1971	19, 418
Calcium and gangliosides in membrane function.	MacDonald, Robert C., Northwestern University, Evanston, Ill.	1970	20, 165
Amyotrophic lateral sclerosis—immunovirologic models.	Lehrich, James R., Massachusetts General Hospital, Boston, Mass.	1971	52, 589
Psychological changes and cerebral lesions....	Reitan, Ralph M., University of Washington, Seattle, Wash.	1970	23, 395
Mechanisms involved in primary demyelination.	Farrell, Donald F., University of Washington, Seattle, Wash.	1972	35, 708
Electron microscopic and immunologic studies on CSF.	Herndon, Robert M., Johns Hopkins University, Baltimore, Md.	1972	65, 736
Ultrastructure of cell surfaces in neuropathology.	Collins, George H., University of Florida, Gainesville, Gainesville, Fla.	1972	38, 120

CURRENT MULTIPLE SCLEROSIS AND RELATED RESEARCH—INTRAMURAL RESEARCH

Title of project	Principal investigator	Funds
Amyotrophic lateral sclerosis (ALS) and other lower motor neuron diseases.	Engel, W. King; Warmoltz, John; Mendell, Jerry.	\$41, 540
Immunochemical studies in multiple sclerosis.....	Sammeck, Rolf.....	32, 630
Studies on myelination in the central nervous system.....	Brady, Roscoe.....	14, 830
Glycoprotein metabolism in the myelinating central nervous system.	Quarles, Richard.....	62, 300
New epidemiologic study of multiple sclerosis in U.S. military veteran population.	Brody, Jacob A.....	35, 848
Amyotrophic lateral sclerosis in veterans.....	do.....	9, 887
Epidemiologic and immunologic study of families of subacute sclerosing panencephalitis patients and families of matched controls.	do.....	49, 541
The epidemiology of motor neuron disease in the United States.	do.....	5, 043
Serological studies of common viruses in cases of multiple sclerosis (MS) and controls.	do.....	64, 373
Studies on amyotrophic lateral sclerosis/parkinsonism-dementia complex of Guam (ALS-PD).	Brody, Jacob A.; Reed, Dwayne; Holden, E. Michael.	37, 081
Twin study of multiple sclerosis: An epidemiologic inquiry....	Bobowick, A. Roger; Brody, Jacob A.....	7, 416
Genetic analysis of family data on Guam ALS and PD cases....	Reed, Dwayne M.; Brody, Jacob A.; Holden, E. Michael; Eldridge, Roswell.	22, 249
A search for autoimmune mechanisms in the pathogenesis of chronic neurological diseases by the use of peripheral lymphocytes.	Brody, Jacob A.; Nemo, George.....	9, 878
Neurological diseases other than ALS/PD on Guam.....	Holden, E. Michael.....	7, 410
Stateside Guamanian study.....	Brody, Jacob A.....	4, 746
ALS among non-Chamorros after residence on Guam.....	do.....	14, 833
Geographic distribution of neurologic diseases within the United States.	Reed, Dwayne.....	7, 712
Causes of death among siblings of MS and ALS patients.....	Brody, Jacob A.....	9, 790
Multiple sclerosis distribution and patterns.....	Brody, Jacob A.; Reed, Dwayne.....	19, 775
Intrauterine inoculation of fetal monkeys with tissues from patients with chronic diseases and infections.	London, William T.; Horta-Barbosa, Luiz.....	88, 995
Immunologic studies of congenital infections and chronic infections.	Horta-Barbosa, Luiz; Fuccillo, David A.; London, William T.; Sever, John L.	94, 930
Isolation of infective agents from chronic diseases.....	do.....	115, 693
Clinical studies of chronic infections of the central nervous system.	Sever, John L.; Fuccillo, David A.; Ellenberg, Jonas.	89, 020
Slow, latent and temperate virus infections.....	Gajdusek, D. Carleton; Gibbs, Clarence J., Jr.	207, 655

OPPORTUNITIES IN MULTIPLE SCLEROSIS RESEARCH

The mystery surrounding the cause of multiple sclerosis continues in spite of many leads, some of which have been pursued for many years. It has been known that the incidence is much higher in colder climates throughout the world than in warmer areas. When people migrate from a high risk to a low risk area, the age of 15 appears to hold some magic which is not understood. As an example, when people migrate from Germany which is a high MS risk area to Israel which is a low risk area, their level of risk relates to the area they lived in prior to age 15.

Past studies have concentrated on the movement of people from high to low risk areas. New studies are now seeking to determine whether the same findings will prevail when people move from low to high risk areas. Will the age of 15 continue to be an important factor also? Studies are now underway of Vietnamese who have immigrated to Paris and of Indonesians now living in the Netherlands.

A further review of some of these epidemiological studies indicate that only the most severe or highly visible cases were reported. It appears that many persons with only mild symptoms were not included. This may be significant not only in relation to the number of cases but may also indicate that for many persons the disease is not the serious degenerative neurological disorder that it is for some. Perhaps many more persons than previously estimated have the disease and are able to control the symptoms with mild medication.

Investigators conducting multiple sclerosis research are looking for a virus or viruses believed implicated in some way in the etiology of MS. Research on viruses has been spurred by the discovery that four neurological diseases of previously unknown origin have been shown to be transmissible by infection. In two of these diseases, viruses have been isolated and identified.

Despite the popularity of the viral concept, no highly suspect virus has ever been recovered from multiple sclerosis patients. Such recovery may be hampered by the nature of multiple sclerosis itself. Because it is usually a long-term illness, brain biopsies are rarely performed during an acute phase. Almost all research has been done on autopsy material.

Vaccinia virus (from smallpox vaccination) is found in the spinal fluid of more than half of all MS patients. A number of investigators have also noted consistently higher antibody levels against many viruses in multiple sclerosis patients than in controls. Does this point to an infection or immune mechanism as being involved in the etiology of the disease?

Further studies are needed to clear up the many questions raised by this research. It is hoped that a study can be repeated in a compact, isolated area where the population is relatively stable and dense and where a given strain of measles virus is more likely to infect all persons in the community at the same time. Such an area is the Orkney and Shetland Islands which have an extremely high prevalence rate (240 per 100,000) of multiple sclerosis and a well-studied and defined patient population.

The search for a viral agent is closely related to the study of multiple sclerosis as an autoimmune disease in which the system that protects the body against infection becomes sensitized against nervous tissue and attempts to destroy it. It is believed that autoimmunity may be an inappropriate response to infection. It is imperative that additional attention should be given to research on the reaction of the immunological system of the body to infection and the autoimmune response to substances present in the brain.

For many years, a model for studies of autoimmune disease affecting the brain and spinal cord has been a disease called experimental allergic encephalomyelitis (EAE) which can be produced in laboratory animals. It is now possible to prevent or suppress this disease through the use of certain compounds. Since EAE is not the same as MS, how relevant is this work? Can similar compounds be developed to prevent or suppress symptoms of multiple sclerosis?

MULTIPLE SCLEROSIS IN-HOUSE INVESTIGATORS, THEIR EDUCATION AND TRAINING
National Institute of Neurological Diseases and Stroke

David M. Asher: Jan. 1955: Graduated from public high school, Chicago, Illinois; June 1959: A.B., biology, magna cum laude, Harvard University; June 1963: M.D., Harvard University; 1963-64: Intern, medicine, King County Hospital, Seattle, Washington; 1964-65: Junior resident, pediatrics, Boston City Hospital, Boston; 1965-66: Junior resident, pediatrics, Massachusetts General Hospital, Boston.

A. Roger Bobowick : June 1958: Fairfield College Preparatory School; June 1962: A.B., University of Pennsylvania; June 1966: M.D., Tufts University School of Medicine; 1966-67: Straight Medical Intern, Yale-New Haven Hospital; 1967-70: Neurology Resident, Yale-New Haven Hospital.

Roscoe O. Brady : 1941-43: Pennsylvania State University; 1944-47: Harvard Medical School; June 1947: M.D., Harvard Medical School; 1947-48: Internship, Hospital of the University of Pennsylvania; 1948-49: University of Pennsylvania Graduate School.

Jacob A. Brody : June 1948: Graduated from Poly Prep. Country Day School; June 1956: B.A., cum laude, Williams College; June 1956: M.D., State University of New York, Downstate College of Medicine; 1956-57: Intern, Roosevelt Hospital, New York.

Ronald F. DiGiacomo : Jan. 1958: Graduated from high school; June 1959: Agriculture major, Utah State University; June 1960: Agriculture major, Texas Christian University; Sept. 1961: Pre-medical, St. John's University; June 1965: V.M.D., University of Pennsylvania; June 1966: Pathology graduate program, University of Chicago.

Roswell Eldridge : 1955: B.A., Haverford College, Haverford, Pennsylvania; 1960: M.D., University of Rochester, Rochester, New York; 1961-63: Intern, Resident, Department of Medicine, Dallas Veterans Administration Hospital, Dallas, Texas; 1963-66: Human Genetics, Johns Hopkins University, Baltimore.

Jonas H. Ellenberg : 1961-62: University of London; 1962-63: B.S., Economics, University of Pennsylvania; 1963-64: A.M., Statistics, Harvard University; 1964-70: Ph.D., Statistics, Graduate School of Arts and Sciences, Harvard University.

William King Engel : 1948: University City (Missouri) Senior High School; 1948-51: B.A., biology, Johns Hopkins University, Baltimore; 1951-55: M.D., C.M., McGill University Faculty of Medicine, Montreal, Quebec, Canada; 1955-56: Internship, University of Michigan Hospital, Ann Arbor, Michigan (Rotating Internship with Neurology major).

Richard Ferber : 1965: B.A., Harvard College; 1970: M.D., Harvard Medical School; 1970-71: Internship in pediatrics, Children's Hospital Medical Center, Boston, Massachusetts.

Larry Duane Frye : 1965: B.S., Marietta College, Marietta, Ohio; 1966: Summer Course, Bermuda Marine Biological Station, Bermuda; 1969: Ph.D., Johns Hopkins University, Baltimore.

David Anthony Fuccillo : June 1948: Graduated Winthrop Senior High School, Winthrop, Massachusetts; 1949-53: B.S., University of Massachusetts, Amherst, Massachusetts; 1953-55: M.S., University of Massachusetts, Amherst, Massachusetts; 1957-60: Ph.D., Microbiology, Purdue University, West Lafayette, Indiana.

Daniel Carleton Gajdusek : 1939-40: Marine Biological Laboratory, Woods Hole, Massachusetts; 1943: B.S., Biophysics, University of Rochester; 1946: M.D., Harvard Medical School; 1946-47: Intern and Resident, Pediatrics, Babies Hospital, Columbia-Presbyterian Medical Center, New York; 1947-48: Resident in Pediatrics, Children's Hospital, Cincinnati; 1948: Post Doctorate, Physical Chemistry, California Institute of Technology; 1949-51: Resident, Clinical and Research Fellow, Pediatrics, Children's Hospital, Boston.

Clarence Joseph Gibbs, Jr. : 1943: Diploma, St. John's College Preparatory School, Washington, D.C.; 1950: A.B., Biology, The Catholic University of America, Washington, D.C.; 1952: M.S., Zoology, The Catholic University of America, Washington, D.C.; 1962: Ph.D., Microbiology with minors in Zoology and Ecology, The Catholic University of America, Washington, D.C.

John J. Hooks : 1965: A.B., Catholic University, Washington, D.C.; 1967: Masters, Catholic University, Washington, D.C.; 1970: Ph.D., Catholic University, Washington, D.C.

Luiz Hildenbrando Gomes Horta-Barbosa : 1958: D.V.M., National School of Veterinary Medicine, Rio de Janeiro, Brazil; 1962: Pan American Center for Foot-and-Mouth Disease, WHO Project, Rio de Janeiro, Brazil; 1964: Bacteriology Laboratory, Inspection Division for Animal Origin Products, Belo Horizonte, Brazil.

William Thomas London : June 1945: Graduated Hickman High School, Columbia, Missouri; June 1958: B.S., D.V.M., University of Missouri, Columbia, Missouri; August 1965: M.S., Veterinary Pathology, Purdue University, Purdue University, Lafayette, Indiana.

Jerry R. Mendell: 1962: B.S., University of Texas, Austin; 1966: M.D., University of Texas, Southwestern Medical School, Dallas; 1966-67: Internship, Columbia Presbyterian Medical Center, New York; 1967-69: Residency in Neurology, Neurological Institute, New York.

George J. Nemo: 1957: Graduated from high school; 1961: B.A., St. Vincent College; 1965: M.S., Catholic University of America, Washington, D.C.; 1971: Ph.D., Catholic University of America, Washington, D.C.

Richard Hudson Quarles: 1957-61: A.B., Chemistry, Swarthmore College, Swarthmore, Pennsylvania; 1961-66: Ph.D., Biological Chemistry, Harvard University.

Dwayne M. Reed: 1955: B.A., University of California, Berkeley; 1960: M.D., University of California, San Francisco; 1961: Internship, Gorgas Hospital, Panama Canal Zone; 1962: M.P.H., University of California, Berkeley; 1969: Ph.D., University of California, Berkeley.

John Louis Sever: June 1948: Graduated University of Chicago High School, Chicago, Illinois; 1948-52: B.A., University of Chicago; 1952-57: M.D., Northwestern University Medical School, Evanston, Illinois; 1953-57: B.S., M.D., Ph.D., Northwestern University Graduate School; Evanston, Illinois; Medical School, Chicago, Illinois; 1957-58: Rotating Internship, Evanston Hospital, Evanston, Illinois; 1958-59: Residency in Pediatrics, Evanston Hospital; 1959-60: Residency in Pediatrics, Chicago Children's Hospital.

John R. Warmolts: 1951-55: A.B., University of Michigan; 1955-59: M.D., University of Michigan; 1959-60: Internship, Naval Hospital, Philadelphia, Pennsylvania; 1960-61: Residency in Neurology, Naval Hospital, Philadelphia.

Stephen Lee Wiesenfeld: 1962-66: B.A., Anthropology, University of California, Berkeley; 1966-70: M.D., University of California Medical Center, San Francisco, California; 1970-71: Internship, San Joaquin General Hospital, Stockton, California.

Mr. ROGERS. Our next witnesses are from the National Multiple Sclerosis Society: Dr. Richard L. Masland, professor and chairman, department of neurology, Columbia University; Miss Sylvia Lawry, founder and executive director of the National Multiple Sclerosis Society; and Mr. Charles W. V. Meares, senior vice president of the National Multiple Sclerosis Society.

We welcome you to the committee. If you would care to take seats at the table, we will be pleased to receive any comments you might desire to make.

STATEMENT OF A PANEL REPRESENTING THE NATIONAL MULTIPLE SCLEROSIS SOCIETY: DR. RICHARD L. MASLAND, PROFESSOR AND CHAIRMAN, DEPARTMENT OF NEUROLOGY, COLUMBIA UNIVERSITY; CHARLES W. V. MEARES, SENIOR VICE PRESIDENT, NATIONAL MULTIPLE SCLEROSIS SOCIETY; AND SYLVIA LAWRY, FOUNDER AND EXECUTIVE DIRECTOR, NATIONAL MULTIPLE SCLEROSIS SOCIETY

Dr. MASLAND. Mr. Chairman, I am Dr. Richard L. Masland, chairman of the Department of Neurology at Columbia University. I was formerly director of the National Institute of Neurological Diseases and Stroke, at that time Blindness. I appreciate very much this opportunity to testify.

I find myself now on the firing line and face to face every day with patients suffering from multiple sclerosis. If I speak with some emotion it is because it is a terrible and frustrating experience.

We are not speaking here of death. We are speaking of dependency of young people stricken in the early years of life and destined to be increasingly dependent over a period of 10, 20, or 30 years.

THE TIME IS RIGHT

Multiple sclerosis is a disease whose time has come. We have the knowledge if we can exploit it to find the cause of this disease and an effective treatment. That is the reason why I feel that the time has come for a focused effort.

THE RESOURCES ARE AVAILABLE

Over the last 20 years we have built and created in this country a fantastic national research program. The National Institute of Neurological Diseases and Stroke in particular has had a very powerful training program, the purpose of which has been to prepare people to do research on diseases of the nervous system.

THERE IS NEEDED A FOCUS ON MULTIPLE SCLEROSIS

This training program is paying off and has paid off. The people and the resources are available. In my view they are not adequately being exploited. That is the reason why we need a commission.

As has been brought out in this recent testimony, the Institute has a very broad mandate. There are hundreds of neurological diseases. There needs to be a mechanism whereby the effort can be focused. That is why I feel the need for a national commission.

Mr. ROGERS. Thank you, Dr. Masland.

Mr. Meares?

STATEMENT OF CHARLES W. V. MEARES

Mr. MEARES. Mr. Chairman, I am Charles W. V. Meares, a volunteer member of the board of directors of the National Multiple Sclerosis Society and at present its senior vice president. In my business life I was, until my retirement last week, chairman of the board of New York Life Insurance Co.

I appreciate this opportunity to appear before your committee to give you some of my views on the problem of multiple sclerosis. I do this from my dual background as a lay member of the National Society's board and as an insurance executive.

Fortunately, I have never had any personal family or close friend involved with multiple sclerosis. I first joined the board of directors of the National Society because I happened to hear its then medical director describe the devastating effects of this mystifying disease.

I was so impressed with the need to do something about it that I felt moved to give to the society what help I could for a year or two. Eighteen years later I am still impressed with that need and I am more active than ever in this Society's work.

Since joining the board in 1954 I have become increasingly conscious as an insurance man and employer of the impact multiple sclerosis has not only on the patient but on the family as well. Let me mention one incident to illustrate part of the financial aspect and that is not the worst aspect in my opinion.

Until recently, New York Life's major medical insurance program for its 9,000 employees and their families provided for a lifetime maximum benefit of \$25,000 for each individual covered. In 20

years of operation of this program no one had ever run over that \$25,000 limit.

But a year ago last October my personnel director told me that the wives of two employees were about to do so. In each case the disease was multiple sclerosis. This story has at least a partially happy ending in that New York Life raised the limit of its coverage to \$50,000 so that both of these patients are still receiving benefits.

The medical expense is only part of the financial picture. Both of the husbands involved in these two cases felt compelled to take early retirement in order to be able to stay home with their wives and thus keep the cost of home nursing care to the minimum.

The case history of one of these patients, Mrs. Jessica Morgan of Ridgewood, N.J. is a fairly typical example of the effect multiple sclerosis has on its victims and their families. In some ways it is a most heart rending story.

In others, particularly as it describes Mrs. Morgan's indomitable spirit and devotion of her husband and sons, it is a very heart warming story indeed. I won't take the committee's time to read it today but I would ask that it be entered into the record.

I hope that every member of the committee will be able to find the time to read it. In getting back to the financial impact of MS for a moment, it may be interesting to the committee to know that it is estimated that it costs our economy \$2 billion a year, mostly through, the loss or reduction of earning power of patients and their families.

The fully happy ending of the multiple sclerosis story can come only on the day when we can tell its victims that we have found the cause and cure of their affliction. I firmly believe that the establishment of a national commission on multiple sclerosis will advance that day by years.

Thank you for letting me appear before you.
(The case study referred to follows:)

EXHIBIT I

CASE STUDY OF AN MS PATIENT: JESSICA MORGAN, RIDGEWOOD, NEW JERSEY

Jessica Morris was born in the summer of 1905 to a Connecticut family whose heritage is almost as old as America itself. Soon after she was born, her family moved to Ridgewood, New Jersey, where she has lived ever since.

In most ways, the early years of Jessica's life were typical of many Americans. She attended neighborhood schools, studied music at a large university, and after graduation in 1930 became supervisor of the music program in the Westwood School System. She played the piano as many people do, and regarded the family's Steinway as a prized possession. She excelled in sports and particularly enjoyed swimming and skating. In 1931, she married a rising young attorney and, within the next several years, she bore him two sons.

Jessica, now Mrs. Kenneth Morgan, is a typical victim of multiple sclerosis, stricken in her most productive years.

The earliest symptoms of the disease became apparent as long ago as April of 1931 when Jessica was only 26. For years thereafter, she would be struck by baffling spells of partial blindness, sometimes lasting as long as six months, and by sudden losses of balance and of motor control. Her fingers lost much of their mobility, her shoulders began to sag, her waist lost all sense of feeling, her right leg began to drag. By the later years of the 1940's, she was unable to drive, she began stumbling and then toppling over in stores, on buses, on the street, and finally, down a flight of stairs in her home. So rudimentary was the medical knowledge in the field of MS that a series of physicians failed to diagnose her illness until 1951, when it had reached its more advanced stages. By 1952, Jessica Morgan was almost bent over double, unable to hold her back and neck up,

and largely confined to a wheelchair. One of her sons left college for nine months to become his mother's nurse.

As early as 1950, Mr. Morgan began to cut back on his legal responsibilities, worked shorter hours, and avoided the more significant and taxing assignments in order to care for his wife. Though his employer was understanding, Ken nevertheless gave up promotions and salary increases and, as the years passed and his wife's health declined, he sacrificed a productive and rewarding career.

In 1958, paralysis of her bladder confined Mrs. Morgan to a bed from which she could only be removed with a sophisticated pulley. In the years since then, she has remained almost totally paralyzed and in need of constant and expensive medical care. Although Ken Morgan's group insurance has paid over \$42,000 in claims, the strain on the family's finances has been enormous.

Mrs. Morgan still lives on a quiet tree shaded street in Ridgewood. It's been twenty-five years since she lost the ability to do so many of the things she loves. Her Steinway piano still sits in her living room, her memories of the world outside her room are still clear and precise. She can no longer move at all, except, surprisingly, to shift her head, smile brightly, and tell you she's lucky!

She's lucky, she says, because though they've spent almost everything they inherited, earned, or saved, their sons managed to finish school and they still have their home. She's lucky, she says, because she has a husband and children who sacrificed a great deal for her and would do it all again; and because she has many friends in Ridgewood, one of whom has even sent fresh flowers to her home every Friday morning for nearly two decades.

But most of all, Jessica Morgan to this day claims to be a proud and happy person because she and her family "have made a success of this enormous trial."

Amazingly, Jessica Morgan voices only one regret, only one word of complaint—that through all her years of paralysis, no real progress has been made toward the prevention of MS. She's pained mostly by the realization that neither the quick death of a figure as illustrious as Lou Gehrig, nor the hundreds of thousands of unfinished tragedies like her own, have prompted the broad national effort necessary to conquer this crippling disease.

Mr. ROGERS. Thank you very much, Mr. Meares for appearing for your interest and devotion of time on a volunteer basis to such an excellent cause. The committee commends you, certainly.

Mr. Nelsen?

Mr. NELSEN. I have no questions.

Mr. ROGERS. Dr. Carter?

Dr. CARTER. Mr. Chairman, I want to congratulate the distinguished gentleman on his presentation and further compliment him on his thoughtfulness for the victims of multiple sclerosis and for raising the amount for which the company would be liable from \$25,000 to \$50,000. It was a humanitarian thing to do. I only hope that other companies besides the New York Life would think of these things.

Mr. ROGERS. We are very pleased to have the founder and executive director of the society, Miss Sylvia Lawry.

STATEMENT OF SYLVIA LAWRY

Miss LAWRY. Mr. Rogers, committee members and Congresswoman Heckler, I am deeply grateful to you for the attention you are giving to our mutual problem, multiple sclerosis.

The question has been raised about whether we are at the juncture in terms of promising leads to move forward in a dynamic, aggressive way. If I may, I will quote from my scientific mentor, Dr. Houston Merritt, who was dean of Columbia College of Physicians.

He was Dr. Masland's predecessor as head of the New York Neurological Institute and termed the father of neurology today. His statement made at our national conference was this, 25 years ago the general public was only vaguely aware of multiple sclerosis and little

if any significant research was being done. In the years since the expansion the interest has been phenomenal. We are now on the threshold of solving the problem."

I want to tell you why it is that we feel so strongly, that the national commission is warranted and needed to bring us beyond the threshold to the final states in the story of multiple sclerosis. Because of the manifold efforts already expended, the belief is strongly held among our scientific advisers that with adequate emphasis the problem of multiple sclerosis could be solved.

This cannot be said with an equal degree of assurance about other problems in the neurological field. The intent of the commission is to bring to bear the fullest application of scientific manpower and resources to realize as soon as possible and the least possible cost conquest of multiple sclerosis thereby aiding NIH, the National Institutes of Health, and our society in fulfilling one of our main purposes.

For these reasons a national commission will direct itself to multiple sclerosis and related diseases alone and apart from other neurological diseases. Government support of vital programs carried out through the National Institute of Neurological Diseases and Stroke, programs which embrace a spectrum of some 200 disorders.

It is quite appropriate that you raise the question about the structure of our institute. It is a major undertaking and it is necessarily diffuse and results in a preponderance of research best classified as fundamental research in the medical society.

While such research is valuable, its unquestioned virtue seems to be that it does produce leads that solve problems of immense personal and economic consequence. However, the history of medicine is replete with examples of such leads of great practical significance being literally ignored for years until social pressures have stimulated their exploitation.

Some examples are penicillin for the treatment of infectious disease motivated by the need to treat vast numbers of infections occurring during World War II and vaccines for the prevention of poliomyelitis, the motivating force being the National Foundation for Infantile Paralysis.

We believe that leads are in hand which can be exploited and which give promise of being able to be developed new practical means for the control of multiple sclerosis. In the absence of a commission, these leads will not be exploited as expeditiously, as imaginatively and as fully as required to obtain the earliest possible control for this disease.

It must be acknowledged that the combined efforts of the National Institute of Neurological Diseases and Stroke and the National Multiple Sclerosis Society have not succeeded in generating the requisite social pressure to induce investigators with the requisite capabilities and facilities to undertake an all-out effort to solve the problem of multiple sclerosis.

The prestige of the national committee is needed to accomplish this end. Productive research directed at a given disease requires effective communication and mutual respect and understanding among the various disciplines capable of contributing to solving the mysteries obstructing the complete control of the disease.

Scientists are trained in a particular discipline and tend to direct their thinking within their own field of specialization rather than to

attract a specific disease which requires for its success a mutually disciplinary approach.

A commission with a specific mandate from your committee will have the requisite influence to accomplish this end. Further, the requirements with respect to the capabilities of personnel and physical facilities to uncover a promising lead and to exploit that lead to a logical conclusion generally are different in many respects.

It would appear that the creation of positive attitudes on the part of scientific personnel and the development of meaningful plans for maximally productive research could be expended most effectively by a commission.

In some places the full potential of promising leads for further research is seldom recognized except by the prepared mind seeking a practical solution for a specific disease. A national commission aimed at multiple sclerosis and multiple sclerosis alone will maximize the probability of achieving a major success.

The principal aim of the commission on multiple sclerosis is not merely to direct more of the broad type of government spending as at present on a wide spectrum of diseases but to inspire investigators to fully exploit what leads presently exist.

I was asked a question yesterday by an official of HEW that why is it that such a major problem as multiple sclerosis obviously has had so little of the focusing of attention by the scientific community of our country today? I told this individual this was the question I asked of the scientific community myself 25 years ago.

The predecessor to Dr. Masland as head of the Neurological Institute when asked this question by me pointed to a \$10 check which came to him several days ago from a MS patient who wanted this money to be used for MS research.

In conflict with the policy of that institution's board of directors which set down the premise that in view of our deficit budget—and this is a characteristic illness of all medical schools and higher institutions today—our research efforts need to be expanded in the directions of where public support in dollars are available.

I think this same situation exists today. Thank you very much.

Mr. ROGERS. Thank you very much for your excellent testimony. I think the committee is impressed with the need for action.

Mr. NELSEN?

Mr. NELSEN. I have no questions but certainly I wish to express a thank you. With the wide experience that you so obviously have, you have impressed this committee with the need for attention to the problem.

Mr. ROGERS. Dr. Carter?

Mr. CARTER. I wish to congratulate the distinguished lady for her presentation and for her dedication which is absolutely necessary to the solution of our problem, which in this day and time in many instances is sadly lacking.

Mr. ROGERS. Thank you so much for your presence here today. It is most helpful to the committee.

Mr. MEARES. Thank you.

Mr. ROGERS. Our next two witnesses are Mr. Barry Corbett, chairman of the Massachusetts Jaycee Multiple Sclerosis Campaign and Robert Baptiste, associate member of the Attleboro Jaycees. We welcome you, gentlemen.

Our time is very limited. If you would like to file your statements for the record, they will be made a part of the record without objection. If you would, please highlight for us the main points that you think the committee should see.

STATEMENTS OF ROBERT BAPTISTE, ASSOCIATE MEMBER, ATTLEBORO JAYCEES, AND BARRY CORBETT, CHAIRMAN, MULTIPLE SCLEROSIS CAMPAIGN, MASSACHUSETTS JAYCEES

Mr. BAPTISTE. Mr. Chairman, thank you very much.

Distinguished members of the subcommittee, I am very proud to be here today. It is quite an honor, that is to Margaret Heckler. I would like to first of all enter this for the record.

Mr. ROGERS. Without objection it will be made a part of the record following your verbal presentation.

Mr. BAPTISTE. This is a production put together by a MSeer himself who was confined to a wheelchair. I wrote up his own particular feelings on the subject. I would like to enter that into the record.

Mr. ROGERS. We will be delighted to receive it.

Mr. BAPTISTE. I feel I am one of the more fortunate people to be here today. The reason I say more fortunate is because I could be confined to a wheelchair, I could be confined to a bed at this time. Fortunately, I am not. I am here visiting with you.

A lot of the things have been explained already in testimony by the preceding witness. To be concise, I will go right over it very quickly to save time.

It has been mentioned that this primarily afflicts the 20- to 40-year-old bracket, which is true, but it has no favorites. It can hit you before 20 and it can hit you after 40. It plays no favorites whatsoever. It can hit you without any warning whatsoever.

In my own case I got up at 7 o'clock one Sunday morning. I had my first attack at 9 o'clock, 2 hours later. It can hit you as if a shotgun was pointed at you and the trigger was pulled and wherever the pellets hit you, this is where the trouble occurs.

This is a progressive disease and incurable, as has been stated, at this time with no known medication known to man. There is hope. There is definitely hope. All the researchers throughout the world, throughout the country have definitely made this statement.

There is definite hope if we can get the necessary fund to conduct the necessary research in this field. We definitely should because, as had been stated, this hits primarily the age group between 20 and 40, the time of your life when it is required by our system to be the most productive.

You are just shot down. This is a tragedy in my estimation. There again I have this disease but I honestly in all candor really feel that this is tragic when here are these people that you need for your system, for your well-being, the whole country needs them and they are shot right down, they are wiped out.

That is definitely a tragedy. One only has to have a dear friend afflicted with this beastly disease to realize the many tragedies that do result from it. There are so many that it would take too long to explain them to you. I will not bother to get into that.

I feel that curtailment of any medical research in the health field is very difficult to justify. It is very difficult for anyone to justify. It

is especially puzzling in this MS field where, I would like to reiterate, it definitely affects the young people of our Nation.

We could really extend the lives of millions of Americans who otherwise are doomed to die prematurely if the appropriate moneys are appropriated and a program with us is conducted, a commission is assigned and possibly the cause and cure with us is found.

Definitely we could extend the lives of many millions of Americans. MS needs a really fresh new optimistic outlook. In the past, ideas were based primarily on the more severe hospitalized cases and we did not pay too much attention to the young people who were afflicted with this disease. We are long overdue to focus attention on these young people.

I would like to read to you a quote which I recently received from a well-known person right here in Washington. He said, "I feel the Federal Government has both the obligation and the opportunity to provide the leadership in developing a solution to this problem. I feel that we have the expertise and the necessary moneys to accomplish this goal."

I could not agree with him more. How can you help? Very simply, by endorsing Congresswoman Heckler's bill and using your leadership and guidance in seeing to it that this bill does not get bogged down anywhere along the line and in the fastest possible way get this thing through.

This would be a tremendous gift to humanity if this were done, a great gift. I realize that all of you have in the past definitely contributed a great deal towards the good of humanity. I am asking you for one thing, to help me contribute a small bit on my part by helping all MSers through the country.

It would be my contribution to the MSers throughout the world. I really feel that if during a person's lifetime he can not contribute one small bit, his lifetime has not been fulfilled. That may sound corny to a lot of people, but I really believe that, if you can't contribute one small bit.

This is all I am trying to do, to contribute one small bit. I am sure all of you have definitely contributed an awful lot in the past to humanity. Otherwise, you would not be sitting where you are today.

I know you are pressed for time, Mr. Chairman. I am going to close with that final statement and let my dear friend Barry take over for the Jaycees.

I thank you very much.

(The article referred to follows:)

MULTIPLE SCLEROSIS, THE BEASTLY CRIPPLER, FROM A PATIENT'S POINT OF VIEW

Author: Anthony Gwynne Bissanti

INTRODUCTION

Multiple Sclerosis is truly a most dreadful disease which strikes mainly against young adults between the ages of twenty to forty years of age. It is a crippler, a depriver, a spoiler, which actually and realistically takes the legs from under both men and women in the prime of life. Multiple Sclerosis does more than cripple young adults—its effects are most terrifying. I write this book to beg all capable people everywhere to launch a massive attack upon M.S.—its cure is long overdue.

We are an affluent nation; not only monetarily and economically, but because of our great possession of intelligencia and advanced medical equipment. For ex-

ample, we are presently using Atomic Energy Scanners along with Radioisotopes to determine numerous and varied maladies. We are now capable of traveling the Solar Universe a distance of one-quarter of a million miles from Earth, and return to Earth safely. A most incredible feat most worthy of praise beyond one word or group of words yet devised by Webster or any other lexicographer.

Why can't we amass this tremendous source of intelligent people to attack the enigma—the unknown cause of M.S., thecrippler? I am certainly aware that there are many other dreadful diseases for which we also have no cure as yet. They too require assistance.

I write about Multiple Sclerosis because I have this dreadful disease. I wish to be of some assistance to other people who have M.S. Before one can be of assistance, one should possess a basic knowledge of this malady. Read on... I feel confident that the reader of this book will truly be enriched regarding a disease which has outsmarted mankind for many, many years. When will our nation and other nations priority be "Protect Health"? If we are to remain strong as a nation, should we not make certain that our people are healthy and strong? Let us not turn away and leave over one-quarter of a million people crippled. Throughout the world in excess of one-half million people are crippled by M.S. Help! Ours is truly a need, and our great nation has the economic resources and the medical ability to put us back on our feet.

PREFACE

I wish to dedicate this book to my most devoted wife, Anne, and to our three wonderful young sons: James, age 8; Thomas, age 7; and Robert, age 4.

I express my profound gratitude that I am an American and had the privilege to serve on active duty for my beloved country.

I express my gratitude to Dr. Irving M. Levine, Neurologist with the Veteran's Administration. Dr. Levine's knowledge of M.S. and his untiring efforts are simply far beyond reproach Dr. Levine is the faith, trust, and the hope that each M.S. patient is fortunate enough to be able to receive To us, Dr. Levine is priceless.

I express my gratitude to Dr. Simeone S. Locke, Neurologist, of Boston, Massachusetts. A truly magnificent doctor. I shall always remember Dr. Locke for his brilliance in neurology and medical mannerisms.

To Dr. Walter F. Crowley, my long time family physician of Franklin, Massachusetts. Dr. Crowley was the first to examine me, and immediately recommended that I see a neurologist.

Also, to the crew of Apollo II, Mr. Neil Armstrong, Colonel Edwin Aldrin, and Colonel Michael Collins, along with many brilliant, untiring, engineers and technicians of N.A.S.A., for a feat of inexplicable achievement. I salute you upon your successful landing on the moon. That which was on the eve of mankind's greatest adventure is now accomplished and recorded with the other giant achievements of our great nation.

A PLEA FOR HELP TO THE NATIONAL M.S. SOCIETY

I am taking this opportunity to write this book about Multiple Sclerosis. I shall be happy to learn what progress The National M.S. Society is making to-date. It is my understanding that this society is an organization formulated with its primary intent being to advance the research, and ultimately the development, of a cure for this most enigmatic crippling disease.

I cannot comprehend many things. For example, I read or hear of only limited progress in research—no definite statement as to when the disease will receive the necessary gigantic push and concentration, so that medical men will find the cause and long overdue cure of M.S.

I feel certain that much is being performed in research to find this cure. I do hope someone will take a moment to educate the patients of M.S. as to just what progress the National Multiple Sclerosis Society is making or has made. (i.e. Is the release of a periodical sufficient?)

Thoroughly aware that the disease M.S. strikes the central and autonomic nervous systems, which are enormously complex in their composition, I know that the answer is not easily found. Yet, this dreadful disease presents a huge gap in every aspect of the M.S. patient's life, and in some cases causes broken homes.

In our newspapers we read of governmental priorities relating to our national budget. We have amassed all our efforts to meet a target date set by our late,

dearly beloved President John F. Kennedy, which was to land men on the moon by 1970. This indicates we are capable of launching a huge rocket, bearing an enormous payload, from Earth to a distance of approximately one-quarter of a million miles through the Solar Universe and to return our men safely to Earth. We have, and continue to build, atomic submarines capable of incredible feats, to swim like a fish, and to reach depths in oceans never before accomplished. We have, and continue to build, the fastest jet planes capable of achieving the highest altitudes.

We must therefore conclude that once we gather this great source of intelligent men, we must ask our government to let their project be to cure M.S. so that we can once again let a man feel like a man; to let him walk upon the face of the earth; to once again realize what it is like to walk beside his wife or her husband; and to play with their children.

The dignity of man must come through the realization that he can do and perform as other men do, and not constantly be dependent upon his wife, her husband, and fellow mankind. I am proud that I was able to serve my country, for my country does more for me than I can ever begin to explain.

Ours is the greatest nation. Any dissenters and draft card burners should be more aware as to what a privilege it is to be an American. To answer one of our late presidents, I do ask what I can do for my country, for my country does plenty for me.

I pray to our Lord that someday soon Multiple Sclerosis will be entered within the many rightfully needed priorities. I do not doubt the tremendous significance, both scientifically and militarily, in the need for going to the moon, but we must continue to look forward, never backward.

I ask the Multiple Sclerosis Society to help us in a manner that removes all "stops"; not merely by asking a movie star to stand before a television camera and say, "Won't you please give when your M.S. volunteer calls upon you?". Yes, obviously people will give, but is this enough?

Multiple Sclerosis is an age-old dreadful disease that not only cripples young adults, but it does feats of a most devastating and permanently crippling effect upon numerous other parts of the human body. Perhaps this is the reason for so accurately naming this beastly disease, "MULTIPLE SCLEROSIS". It stops many other parts of the human anatomy from performing their naturally intended functions.

I read an article recently in a newspaper written by an Emeritus Professor of Medicine at one of the country's most leading clinics. The article stated that a number of people had been writing asking about Multiple Sclerosis and that local doctors had told them that they did not know of anything to do. As of this date, there is no cure or treatment for this disease that affects nerves all over the body.

The poignant point I wish to make is two-fold: (1) How little is known of this crippler, and how comparatively little is being done. (2) How victims of M.S. as well as others are being placed in a position where they must ask that an article or two be written about this disease. This apathy towards such a ruining disease must cease, and we all must live and help others to live; not merely to exist day to day.

The same article also relates quite explicitly that in the past twenty-three years, the National Multiple Sclerosis Society has granted more than \$11.5 million to support promising research on M.S. all over the world. I commend the M.S. Society; however, arithmetically this amounts to approximately \$200,000 per year. This disease has outsmarted mankind for more than twenty-three years. Billions have been allocated to the space program—even greater amounts have been swallowed up in the Viet Nam War—why can't we devote at least one of these billions to research M.S.? This crippler has been permitted to spoil the lives of our young adults for too long a time.

I have made a comparison of how much in dollars the National Multiple Sclerosis Society has granted as compared to our space programs and the Viet Nam War. I have asked that any and all stops be removed to find a cure for M.S. Now I am requesting that others, such as the World Health Organization (W.H.O.), National Institute of Health (N.I.H.), the Veteran's Association of Multiple Sclerosis (V.A.M.S.), and people in our great nation, hear my plea. United with one and the same purpose in mind, we shall constitute a strong, gigantic force which will outsmart this monstrous disease.

"Within the lifetime of one generation, science has realized and overpassed every age-old dream of humanity to which it has applied itself.¹ Why are we so

¹ Time Magazine, August 1, 1969.

reluctant to use science to achieve a longer and healthier life; maybe to live for centuries, so that we can see all the wonders that we so glibly talk about? Who can say today that we could not do it?"

The above quotation was written by Steven Lunzer, M.D., of Duke Medical Center, Durham, North Carolina. Dr. Lunzer has portrayed my innermost feelings. I felt it extremely appropriate to quote his writing.

In order to avoid redundancy, I shall cite one more instance relating to the quantity of money and the level of priority that I personally feel M.S. should be allotted. To gain a vivid picture of anything, a comparison is usually made. Let us take the liberty of reiterating or including in this book the amounts some projects are receiving as compared to this awesome disease, Multiple Sclerosis.

"Fort Dietrick, Maryland, employs 2,600 people at the Chemical and Biological Warfare Center. Approximately two million dollars are spent *per day*, including salaries on chemical and biological warfare research and development."²

Just imagine, if you will, what the scientists could do and accomplish with this amount or near this amount for the research of the cause of Multiple Sclerosis. Has this M.S. not ruined enough lives, broken enough homes, crippled enough people, that we should not commence at once to stop this dreadful monster?

At one time, as we are all thoroughly aware, the disease Polio was thecrippler. At that time, Dr. Jonas Salk discovered through research, the Polio Vaccine. Dr. Salk, obviously a brilliant scientist, was able to separate the particular bacillus strain which caused polio. The Salk Vaccine is now in existence and has rid mankind of a most terrifying crippling disease. How can we ever thank Dr. Salk for his superior achievement!

It would appear to me through pure conjecture, that due to a huge amassing of all medical men and scientists, with their command of information derived from research and concentrated efforts, ably determined the cause and ultimately the cure for Polio. What a wonderful manner in which to repay mankind. I salute Dr. Jonas Salk, and just pray that perhaps some day he will help the victims of M.S. so that we not only exist from day to day, but rather we live. I say from experience, "Oh, what is there left of that which was once a man?" As you read the chapter of "Ten Men in a Row", this remark will be recalled to your mind, for reasons one will never forget.

I feel we must move ahead "full speed". We should permit no more young adults to be crippled by M.S. We usually associate M.S. victims with being crippled. The M.S. victim encounters many other difficulties, such as the possible loss of eyesight, to possibly becoming incontinent, plus other horrendous damaging effects upon the human body. M.S. victims require all the assistance that we can possibly gather up. In life, some things are more important than others. I do not pretend to set myself as an authority as to what should come first. But what is more important than helping a human life? To put a man back upon his feet right here on earth? To permit mankind to enjoy the God-given drives which are an inherent part of each man since his birth?

I have read an article about a young girl, aged 26, who had M.S. for the past two years, and she tells that she was not aware that M.S. is such a widespread disease, and further that she believes that she will eventually become able to fully accept M.S. How little do most M.S. victims know, I wonder? How much do some of our neurologists know, I wonder? But, I really would like to know. This feeling of apathy I sometimes experience that perhaps exists toward M.S. victims is very depressing. I hope my feeling is totally unfounded, for the sake of all the afflicted.

It appears, that M.S. is still striking many of our young adults in all walks of life. M.S. strikes the rich, the poor, the middle class, those of average intelligence, and also those of superior intellect. M.S. strikes the professional people as well as the average person. In this one manner of detecting the disease, we have no clues to follow its pattern of social classes or position of a person in life. Quite obviously, these things have no bearing or significance. Scientifically speaking, there is no differentiation as to who could fall prey to this terrible disease.

I am certain there are literally tons of research papers and theorems, and reports, each containing various approaches in our attempts to separate this unknown intruder which turns a healthy, happy man or woman into a life of constantly being deprived of the natural everyday things God intended us to do; the ordinary things which the healthy person, such as I did myself at one time, does. To walk, to stand, to climb the steps to a building, to drive a car, to swim, to walk hand and hand with your wife, to roll on the lawn and play with one's children, and many, many other ordinary things in life.

² The Boston Sunday Globe, Personality Parade Section, written by Walter Scott. September 7, 1969.

M.S. has taken young men and women who were once healthy, happy, and active and who are now people who progressively, with time, become physically worse and much more greatly dependent upon others. (The reader must constantly maintain the very fundamental principle and known fact that medically speaking, no two medical cases of any disease follow the same pattern—what physiologically occurs to one person or M.S. victim may possibly never occur to another . . . this is extremely important to bear in kind.

Multiple Sclerosis appears in the greatest percentage of cases with a Scatoma, or blind spot, in one eye. This Scatoma is usually cured by the use of Steroids and a multivitamin. The eye difficulty disappears after professional treatment, as mentioned above. Obviously, the time element to remedy Scatoma is likely to vary in each and every case. It is usually discovered as a pathogenic ailment of the optic nerve, and is detectable by astute and well trained professional optometrists. The optometrists are trained to look for abnormal characteristics during eye examinations. When an abnormality exists and is noted, then there is reason for concern and additional medical care. In such cases, we find that the optometrist directs this type of medical finding to an ophthalmologist, a medical doctor whose specialty is diseases of the eyes.

In more cases than not, the eye difficulty disappears. Some time later in life, the time element being variable in each case, Multiple Sclerosis overtly begins to manifest itself in some part of the human body, just as though it were a dormant, sedate, fire dragon that has been provoked, and as a result, erupts into seething madness.

The madness in time proves to be strikingly overpowering to the human body; yet is still capable of concealing itself so well, that after many, many years, scientists are still unable to outsmart this unknown intruder to our human body's network of nervous systems. Is there any particular pattern that M.S. follows in more cases than not? Anything that would embark our scientists upon a new research? It seems as though for a great number of years medical scientists have made very little headway in this. I expressly mean research of a constructive nature. A positive method even to employ in our laboratories. Is there a plan? Is there a laboratory testing method?

M.S. preys upon the myelin or fatty tissue substance which surrounds each of our nerves and functions as a protection. For example, the Neurons and Axons are the carriers of messages that are released from our control center the brain. As the brain releases messages, biological impulses are transmitted via this most complex network of nerves, our central and autonomic nervous system, and sympathetic and para-sympathetic nervous systems of the human body. If the nervous systems and their myriad components are damaged or diseased along any of the network, then, correspondingly, we have a natural function of the human body which is not able to perform its normal intended function; to use a phrase, "It just does not get the message." Therefore, it just cannot and does not function. Some M.S. patients could not touch their toes or wrinkle their nose, even if they tried.

The nervous system of the human body is indeed complex. It is composed of dendrites, synapses, axons, neurons, the brain, the spinal cord, the thalamus, afferent nerves, efferent nerves, plus a number of others. Some of these parts of the nervous system are termed "motor nerves," which indicates they are indicative of action, such as workers or carriers of messages to and from the brain, where all feelings and desires originate. Others are termed sensory nerves, which would indicate that once the motor nerves finished their chore of carrying the message to the intended part of the anatomy, that the sensory nerves would take over and tell the intended function of the body it has received the message. Now that the message is received at its destination, physiologically, according to the organ involved, it will render the sensation which is appropriate to that particular phase of the body.

Sensations are psychological states, the product often of many correlated nerve impulses. Let us take for example, what medical men term as receptor end-organs as in the sensation of contact. Each digit or finger, or more technically the phalanges, contain end organs which carry sensations. If a person accidentally touches a hot radiator, the sensation is immediately transmitted to the brain, and the person quickly removes his finger from the hot radiator to rid himself of an unpleasant sensation, which is termed cutaneous sensation, such as to touch anything.

To attempt to determine the rapidity or velocity with which this sensation was carried from an extremity of the anatomy to the control center, or the brain, is simply too perplexing to me; a neurologist is better qualified to answer

such a profound medical question. The human nervous system is so complex in its composition with innumerable minute avenues for messages to travel, plus the chemical processes that must in some manner also enter the question, we must admit that the human body is by far the greatest and most complicated machine ever devised.

It could be said that the human nervous system is as complicated, if not more complicated than a computer. Can you for one moment imagine the quantity of wires and circuits in a computer? Perhaps the computer fundamentally was patterned after our nervous system.

Getting back to the myelin or fatty tissue which surrounds the nerves to protect them, the myelin sheath insulates each and all nerve fibers and prevents the overflow and the loss of nerve impulse. There appears to be some evidence that the myelin sheath plays an important part in the chemical processes involved in the production of nerve impulses.

It appears thus far that the problem of M.S. seems to be here. For some enigmatic reason, this fatty tissue covering our nerves, neurons, axons, and synapses degenerates, breaks down, thus leaving our nerves unprotected in different areas of our body. As this occurs, our biological impulses transmitted from the brain are unable to be carried to their intended destination. They are similar to the telephone wire covering or insulation. If we were to strip away the protective outer rubber coating of insulation and expose the inner numerous wires which transmit the messages, eventually, these inner unprotected wires would be exposed to various elements which eventually would become so damaging to the unprotected inner wires that messages would not be transmitted successfully.

Is this why when an area of our nervous system loses this myelin sheath, the M.S. patient loses control of that part of his body to which the nerve is either damaged or diseased? With M.S. patients, the muscles are intact; however, the message which must come from the nerve to the muscle, for example, to pick up one's leg, never receives the transmission from the brain to the nerve of the muscle involved. As a result, one cannot pick up his leg.

Is it the cause or effect? The thalamus which is located in the lower rear area of the brain has a function which is said to be similar to an electrical "junction box". The question is, is the electrical network our problem, (a part of the nervous system), or is there, let us say, a defect or "short circuit" at the "junction box," or medically, the thalamus. It is like the proverbial question of, "Which came first?" Can medical scientists say?

Perhaps this is too simple a method of logic to attack such a seemingly unsurmountable medical problem as Multiple Sclerosis. If I remember correctly, it was Dr. Flemming who discovered one of our miracle drugs which has saved so many human lives, and how?—purely by accident. For as we know, medical students were the subjects of a perplexing happening in the laboratory. As the medical students were required to grow certain strains of bacteria in a crucible, they would place the crucible with the necessary strains of bacillus, or bacteria, in the required temperature for a required length of time. The medical students would notice this green colored matter which would develop in the crucible dish and kill the growing bacteria or strain of bacillus. Dr. Flemming, very much alert, envisioned immediately the beneficial effects of such a chemical reaction against germs. It was in this way that Penicillin was discovered; one of our still frequently used miracle drugs.

This leads us to the myriad theories Virology now holds. We M.S. patients do pray to our Lord that it will soon be that our professional medical scientists will conquer this terrible unknown that causes so many hardships, sufferings, unhappiness, and even causes marriages that were at one time truly harmonious to turn into broken homes.

We must take drastic measures to conquer Multiple Sclerosis. The time is long overdue * * * let's act now!

In general, we shall always have the three basic comparatives; that is, to rate everything into a category of good, better, and best. Subsequently, one should understand that what I am about to relate does not pertain to all, yet I include it in my book in hopes to express a very poignant point, which I feel has a bearing upon this book's subject matter, Multiple Sclerosis, a tremendously important medical problem which much be outsmarted in order for medical science to become victorious. We should not permit ourselves ever to entertain the attitude that, "Oh well, there is no cure for Multiple Sclerosis. We don't know enough about it; so, therefore, we'll just have to learn to live with it." A feeling of apathy? I have personally run the gamut of medical men. These medical men could not diagnose the disease of Multiple Sclerosis. Those who could diagnose

it as M.S. then proceeded to say there is no cure for M.S., and medical science knows little about the disease. The reader must keep in mind that these statements, although true in every minute sense of the words, obviously does not, I repeat, does not apply to all medical men. I have also had the good fortune to be treated by some of the greatest and most knowledgeable and understanding medical doctors in the Boston, Massachusetts area. What I wish to do is to explain the basic fact that all medical men should make it their business to find out more about M.S.

As one reaches the chapter entitled, "Ten Men in a Row," I am certain that I shall tug at the heartstrings of medical and nonmedical men and women. For here the act of projecting oneself into another person's place, always makes things strike a little closer to home. What would you do if M.S. struck you or one of your loved ones? This is a question I feel you will quickly answer yourself. No help will be needed.

I understand that the disease is a very difficult one to diagnose, although I believe progress is being made in this one important direction. However, to continue with my main point—a consultation with a neurologist was requested to present the neurologist with a specific question. The question presented to the neurologists pertained to incontinency, plus the effect Multiple Sclerosis has upon the patient's sex capabilities, and was there anything that could be done in the event that his virility or potency should or would become affected.

To me, it would appear to be a problem of rather large magnitude, if a young man of about the age of thirty-three could no longer fulfill one of man's strongest inherent drives. At any rate, it was concluded that the neurologists had no answer of any definite substance. Obviously, I realized now that because of nerve involvement, that in more chances than not, there was nothing that could be done until such time as a cure for M.S. was discovered. The parasympathetic nervous system is directly in control of the external and internal sphincter muscles. As a result there are three areas of the body's organs that could be adversely affected to a point of no return: incontinency, or loss of bladder control; possible loss of control of the rectum; and possible loss of man's sexual capabilities. These are my own opinions being advanced, from a M.S. victim's point of view.

Some neurologists are of the opinion that if impotency, or lack of erectile tissues or sexual response occurs in a patient of M.S., which would obviously rule out sexual relations with one's wife due to physiological inability to gain intromission with one's mate. That it follows correspondingly that the M.S. patient loses all desire for sex. The conclusion is that as a result, we have no problem of any magnitude. In other words, we just should accept this unfortunate happening. I wonder if you could at age thirty-three or thereabouts accept this? What do you say to your wife? Do you look at your wife and not have desires? Keep in mind that here we are pitting a psychological problem against a physiological organic problem. It is my opinion that this theory is a fallacy. Once again we must deal in relatives as compared to absolutes. For what applies to one, may, and possibly does not apply to another. Therefore, we also should not take the approach that this theory or theorem applies to all M.S. victims. I strongly believe that all M.S. victims do wish to continue to have the same normal desires and experiences of healthy sexual relationships with one's wife. It is necessary to consider the degree to which this desire is prevalent. We should take into consideration such factors as age of person and the degree of progression of the disease. I grant you there are many factors to be considered. I do vehemently hold fast to my theory, that fundamentally man is endowed with this basic drive of the need for sex; it cannot and should not be treated in a light vein.

It seems that somewhere I have heard that M.S. victims, again we should intelligently state not 100%, but rather high percentage of their marriages either end up "on the rocks" or are severely under stress and strain, the harmony that one time existed may now have changed into frequent strifes with husband and wife. It is truly a gigantic adjustment that must be made, for the life of not only the M.S. victim, but his mate as well has undergone one huge metamorphosis.

To what should we contribute this change? Just endeavor to imagine what some of the most unpleasant things the M.S. victim must cope with each and every day are, in addition to the one factor that he or she is crippled. Sooner or later the wheelchair gets most M.S. patients.

Are the wives of M.S. patients knowledgeable as to what to expect, and the limited physical capabilities of the M.S. patient? Whether it be husband or

wife, they should know. A person who understands a problem is naturally better able to cope with the problem. M.S. victims do not wish to be pitied; they only wish to be understood. They hope that their loved ones will be patient, will be tolerant, will be understanding.

I am taking the liberty of writing about a few things the husband or wife could do to make a M.S. patient's life easier to live, more harmonious, and a complete and happier living of togetherness. Let us attempt to make the best of a difficult disease that M.S. patients did not bargain for. At this time, it is truly unfortunate that one falls prey to M.S., yet it need not be the hopeless end of all life; together we can move along, why not do it?

HELPFUL HINTS

1. Respect the M.S. victim; realize to the fullest possible extent that in his mind he would literally give the world to be able to do for himself, to get out with his wife, to walk beside her, to play with their children, to go anywhere and everywhere as a complete family unit, to church, to a movie, or whatever the case may be.

2. Be completely aware of the patient's physical capabilities. More explicitly, as an example—if you wish to go dancing or swimming, we know that as much as the M.S. patient would not merely wish to accommodate you, but he also would derive tremendous pleasure from this activity, yet he cannot. Be understanding. Select an activity in which you can both take part. For example, visit a friend, go to a drive-in theatre, play cards—but do things together. Do not subject the M.S. victim to unnecessary mental anguish. God only knows the cross he or she bears is truly extreme suffering, both mentally and physically. Help your M.S. loved one. Do not place additional strains and stresses upon him which he is unable to defend.

3. Both persons involved should, with out any reservations, understand each others problems. These problems are naturally a direct cause or effect as a result of M.S. The M.S. victim should also be aware of the fact that his illness has a tremendous effect, not only upon the person afflicted, but also the partner who does not have M.S. The partner not afflicted should be permitted to live his life as close to normalcy as possible. Mediocracy is to attempt to do all things in life that you wish to do, while keeping in mind, up to a specific point, the average or normal intelligent qualities. For example, it is good and it is necessary for the partner of the patient to occasionally get away to the movies with her lady friends; likewise, for a man to have a "night out with the boys." This is extremely good therapy for both persons involved. Yet to overdo, overact, or to take advantage will have an adverse effect. To emphasize the point, for one partner to be out every night and to have social events planned for months ahead of time, events which cannot or do not include the other partner is not good.

4. Communication. Always talk out your ideas and plans; or if they present a problem in context, still talk them out, especially at this point. There is no reason in this world why M.S. patients and their loved ones cannot enjoy a lifetime of joy together. Every person must give a little of something or better still of themselves if they in turn wish to receive something. In reality, M.S. does not alter the man or woman whom you loved enough to marry and bind two lives into one. What is realistically altered is the psyche or the mind of both partners involved as to how willing they are to brace their minds in such a strong manner as to actively accept with resignation the basic facts that yes, my partner in marriage is crippled. Yet reflect for a moment if you will, this person whom you are assisting or pushing in a wheelchair is not just any unknown person. He or she is fundamentally still the exact same person, only at this time the acid test as to how strong is each person to stick by when the stick-to-itness is needed at a most crucial time in one's life. Do you "cop-out" now and cast aside your loved one as you would an old car when it ceased to function efficiently? Do you look for a better functioning model? We must keep in mind that we are not dealing in mechanical objects; hence, we are dealing with humanity. If we are to lick this gigantic problem of M.S., we ourselves must be the greatest protagonists of solidarity. We cannot and must not divide and weaken our cause rather than bind together as one determined group.

We are actually calling out with all our strength for medical scientists to cure M.S. We must at least pull in the same direction expending our time, our efforts, and our own brain-power to assist, regardless of how small the contribution, to being the truest proponents for the cause of M.S. If we the afflicted and crippled

do nothing, how can we possibly expect others to do all for us. We must help too. Give profound thought as to how M.S. affects us and relate our true medical account to our neurologists. We just may form a pattern which could surprisingly set the scientist on the right road. How about Penicillin being discovered, as I previously mentioned. It was purely by accident. Aspirin, another great medicine, sat for years on the shelves of many apothecary or drug stores until medical men realized the beneficial effects of this medicine. Let us never despair. Although the road is difficult, to put it mildly, we must have faith that some day soon medical men will outsmart the dreadful disease M.S. and find a cause and cure. Give the M.S. victim encouragement, understanding, love, and the much needed incentive to continue to live on. This is so easily done. Just let him see that you still love him, and that he still means a great deal to you. Dignity is a most vital characteristic enjoyed and needed by man. Occasionally, moods of depression may affect the M.S. victim; try not to become angry with him. Just understand. Are we so perfect that we do not experience moods of depression over matters much less important than a person who has become crippled? The mood of depression will disappear. It is a natural phenomenon. The M.S. victim will also experience happy elated moments. Share them with him.

5. To understand is another important element. We should do everything in our power to understand. I say this is important because M.S. patients are subjected to various feelings such as numbness in a certain part of their body, or may experience pain of numerous varieties. Do all in your power to understand that these ill feelings are presently not yet known, even by our doctors. Would it be such a tremendous sacrifice on anyone's part to permit a crippled M.S. victim to become low in spirits? Physiologically as well as psychologically it does the M.S. victim good to purge his system, to rid himself of these emotions rather than to allow them to build up within himself.

6. To be deprived is truly a most unhappy and depressing feeling. For example, the M.S. patient must develop a resignation to the fact that he has now become the spectator and not the active participant. It is safe to make the statement that no person can entirely comprehend the inner feelings of a person who is deprived of doing things due to a physical handicap. One cannot completely or even slightly know of this or any challenge till such time as one has first experienced a challenge himself. It is not pleasant to see, to desire, to want, and find oneself physically unable to do anything; quite an awesome unmanly experience.

7. An M.S. patient should always remain strong. He should never give in to his problem regardless of its true magnitude. He should call upon all his God-given natural resources of strength to help him along this path of mental anguish and physical suffering. Yet we should also remember that if God asks us to suffer, He gives us or provides for us to be strong, and takes care of us in many other ways. We should call upon this God-given inner strength to help us to fully accept our problem. To continue along the same line of thought, if we cry—we cry alone. If we live each and every moment of each and every day using every wonderful moment of life that we are able to, then we are doing ourselves and our loved ones a great favor.

Never permit this terrible M.S. to gain the upper hand to the extent that the M.S. victim permits it to change his outlook on life so drastically that it actually becomes "The Spoiler" not only to the patient, but to his family and friends. We should always be the captain of our destiny. My reference to the word destiny is not in the strictest meaning of being able to predetermine one's fate or experiences before they actually occur. By destiny I mean the unflinching determination not to let M.S. be a "Spoiler" completely. Obviously, we realize it does spoil a great percentage of an M.S. victim's life. Yet, let us try to maintain an intelligent balance. We shall live and let live; we shall remain together solidly; let nothing—not even M.S. cause us to divide. Let us not aid this "Spoiler"; let us conquer him and make him disappear. It will take a lot, but we must give all we have if we are to succeed in whipping this beastly crippler. I say any price is worth it to walk again and live a normal life. How about you?

8. A more important discussion is on the unfortunate event of having to realistically play the part of the M.S. victim. We should always maintain foremost in our minds that togetherness is the strata to our needed courage and our much needed happiness. Separatism is the strata to our definitely unneeded lack of love, understanding, happiness, and incentive to live on. The end result, separatism, is the strata to more difficulties, lack of love, lack of understanding. The much required element of incentive is completely lacking. To disagree or argue is a natural emotion. Never keep living in the past—look to the future. Together it brings as much happiness as you could possibly wish for. To take part, to-

gether, as a total family unit. As William Shakespeare wrote, "The world is but stage, and all its men and women merely players". Some roles that we play in real life, for reasons known only to God, are often unpleasant ones. Yet we must play on. (For example, the role of an M.S. victim is indeed horrendously unpleasant, but let us continue on till our role is changed.)

9. Philosophically, I am sometimes tempted to believe in predetermined destiny. We very often hear a sick person say, "Why me? Why did this have to happen to me?" Who knows? Is there an answer? Do we take the approach of what will be, will be? Have you not at one time or another done everything in your power to achieve a certain something, a goal, to be what you really want to be only to find that for some unknown reason it just does not work out? You find yourself in an altogether different profession or situation. Yes, I believe one can ask why, but to expect an answer—that is either for you to determine, or Almighty God. Undoubtedly, there will be a day when all these puzzles will be solved, but at a time when and where someone far superior to you and me will render the answers and fit the pieces of our puzzle together. We will see the picture of our purpose in life—then, and only then, will we truly comprehend the meaning of life. Life does have purpose for every human being.

In my humble estimation, not only from the laws of our greatest scientists and medical men such as Lister, Pasteur, Flemming, Pascal, Descartes, Salk, and numerous others, we, the M.S. victims should have a plan and follow it. Common sense dictates that M.S. patients should and must be the greatest proponent of things he wishes to do. Ask yourself how can I help other Multiple Sclerosis victims? It is always health for the psyche or mind to think of other people's problems; to get away from constantly dwelling upon oneself. It truly is healthy to get one's thoughts away from oneself; to think of others; it is good therapy.

An unoccupied mind is a place for the devil to lurk; a busy, active mind is healthy. Why have fears, phobias, fatigue from worrying? Occupy your mind with things to do and enjoy doing. You will be astonished as to how much better you feel physically.

10. Never allow yourself to become overtired or fatigued. It is not good for the nervous system. Basically, with Multiple Sclerosis ours is a problem of the entire nervous system. Play it smart; know how to help yourself. To get technical for a moment, I shall attempt to explain the reason why M.S. patients should not overtax themselves. Nerve cells are called Neurons. Neurons develop from embryonic cells called neuroblasts. Scattered throughout the cell body and the protoplasm of the larger dendrites is a substance which is known to stain deeply with basic dyes such as methylene blue. It is called Nissl, or chromophilic substance, and it is thought to represent a store of energy. The quantity of this substance is variable depending upon the fatigue of the cell. Consequently, rested cells show a relatively greater amount of chromophilic substance; loss of chromophilic occurs in fatigue, certain fevers, asphyxia, and injury to the axon.

Be sure not to overtax yourself, subsequently aiding M.S. to progress. When you feel tired, just stop whatever you are doing. Get rest to rebuild your nerve cell energy, then you can continue on with your project. Correspondingly, at times it becomes difficult for some patients to accomplish certain things. For example, to button one's shirt, to tie one's children's shoestrings, or to make a knot in one's necktie. Just relax, stop for a moment, and above all remain loose and calm, bearing in mind that excitability and nervousness are affecting your nervous system. Work very slowly and methodically; you will get better results. Why not try it?

In summing up this chapter, I write from my heart to all of you, endeavoring to enlighten your views, trying to teach you to understand your problem better so that you can better live with it. I pray that soon our nation, the entire world, will launch an unflinching, unflinching, unbeatable battle against this beastlycripper and destroyer of young adults. We must attack it with an all out effort; otherwise, it will go on for years if we wait to cure M.S. through research that is funded by small donations. The chance exists that M.S. may grow to greater proportions than we dare dream of. I am aware that it is not contagious—we all thank God for that.

Many words I use, and resulting thoughts that I bring to light, are predominantly for the benefit of all M.S. victims, their loved ones, and their friends. I do hope that many other medical and nonmedical people will also read about this disease and leave the book, after reading it completely, far richer intellec-

tually for having spent their time to learn of a profound medical problem that is capable of dealing humanity a most awesome crippling blow.

I do not for one moment profess nor wish to give the impression that I am so erudite that I dare chastise or indicate that neurologists, neurosurgeons, and research scientists know absolutely nothing about Multiple Sclerosis; or are not endeavoring to find its cause and ultimately its cure. This I do say is being done. My greatest reason for this writing is that the disease Multiple Sclerosis, quite obviously, has eluded professional men for a long time.

The difficulty in solving the problem of this disease is how do we go about detecting the cause? For as we know, once the cause is determined, the cure should be only moments away. What I am attempting to achieve through this writing is to emphasize that M.S. is a most difficult, let us use "unknown" disease to detect. As a result, I am of the definite opinion that the only way in which we are ever going to accomplish curing M.S. is to pull all stops—to gather all the giants of our medical professions as well as throughout the world to solve this disease. We should ask ourselves the question, "Have we ever embarked on an allout attack against this dreadful crippler?"

I feel certain that research has performed a number of experiments to detect M.S., but I would appreciate your reading the questions listed below. I am most certain the questions have been researched; however, the answers are not clear in my own mind.

1. Is it true that in the greatest percentage of M.S. cases the initial onset of Multiple Sclerosis is a disorder of the optic nerve, medically referred to as a Scotoma? This generally occurs in the left eye. The scotoma requires the professional attention of an ophthalmologist, a medical doctor. The disorder of the optic nerve is detectable by optometrists, who in turn refer one to an eye specialist. A scotoma is a blind spot in one's eye. In most cases they are easily cleared up. My question is: Why does this occur or inception of M.S. start here?

2. Is it true that in the greatest percentage of M.S. cases that the left hand becomes slightly affected; yet noticeably affected so that acute normal agility is lost? Why is most cases is it the left hand, the left eye? Is there a pattern to be established of the disease characterizing a set pattern of attack upon the nervous system?

3. Is it true that in the greatest percentage of M.S. cases the loss of bladder control or incontinency eventually reaches the point of from little difficulty to the total loss of control? As you well know, we are now dealing with the parasympathetic nervous system. Why is this so?

4. Why do most M.S. victims experience some difficulty with their bowels? Once again, we deal with the involvement of the para-sympathetic nervous system which affects the internal and external sphincter muscles of the rectum. Again, I feel compelled to ask why in so many M.S. victims does this occur? Are not the above three points prevalent in more M.S. victims than not? Is there not, through the basic mathematical laws of probability, a tangible happening to follow and ask why? In so many cases, why?

5. Why is it that the right leg usually experiences the most difficulty during the initial stages of M.S., then progressively both legs, until such time as the patient is now completely crippled? Why?

6. Is not the frequency of syndromes in M.S. victims enough to launch the much needed massive attack by our scientists upon this beastly crippler? I understand that other people are suffering maladies as terrible as M.S., and in many cases more suffering is experienced and there are more terminal cases. This still does not, will not, and must not permit humanity to give up on M.S. the Crippler. It means, quite fundamentally, that we should as the greatest nation in the world, think more. We must abolish this "Confusion of the budget priorities." We must recognize the plain everyday facts that the sick need to be cared for. Let us do all in our power to insure that we first solve the problems on earth before we expend billions of dollars to go to Mars or some other celestial body. As the cliche goes, "First take care of your own." Help us to walk on earth before we once again reach for the moon.

7. I speak for victims of other unfortunate maladies, too. We have much to do to help our sick. Shouldn't more of our dollars go into projects to help people to live?

8. Our priority budgets continue to spend the greatest percentage upon military defense. Still, as with the unknown in M.S., we face an unknown with defense spending. Is it fear that we fear? Who can say just what is enough in terms of defense spending. Where do we stop? Is there an end to our long line of fears

as to what could happen? We talk of A.B.M. Systems; we talk of MIRV, is there no end to this inexplicable defense against others possible aggressive offensives? Will it ever reach a point of sufficient military weaponry? Yes, I agree we must be militarily superior, but are there not other factors that could be studied in order to make and keep us safe? I realize this is like asking "how high is high". We should all agree upon the concentration of intelligent means rather than entirely upon greater spending for more advanced military hardware or chemical biological warfare. Is it not wise to study this problem? Even though some of our priorities literally have been studied to death, is it that we ourselves do not or cannot see once we are adequately prepared in terms of military strength. Sooner or later, I believe that we shall reach a point in which we arrive at the Law of Diminishing Return.

It is my most humble opinion, that in discussing such a profound problem as the extent to which a nation has reached the point of not only what is military superiority, and without error how much is required or should we have to protect our people in the hypothetical prognostication of all-out nuclear war, I do feel that yes, we should have sophisticated weaponry according to an applicable and sensible "rule of thumb" decided upon by our military strategists. It should be decided upon once and for all. A standardization that is adequate for our nation, the important increment to be even more greatly concerned with is the agility of the human brain, through intelligence and preparedness, "the element of victory is surprise". We can spend money till Hell freezes, but if we are outsmarted by any possible aggressor, then our weapons and the money spent will not be worth a red cent. As we are all aware, in nuclear warfare there is no victor. There is only senseless total annihilation of mankind. Therefore, I conclude that the only victor is the thinker, not the outdoorer. Is there a superior human who can think of a method through which he can destroy our great nation at no expense to his nation? I have yet to read in history of a super human brain that could accomplish devastation to one nation and in return not be devastated itself.

Have we not retained just a little from the horrendous, powerful, devastating effects of World War II? The first atomic bomb on Magasaki and Hiroshima? How, even more powerful, the Hydrogen Bomb is an even greater devastating destroyer. Let it not be kill and be killed; let it be to live and help to live.

Talk can sometimes be a method of direct contrast to its intended purpose. We can find that semantics can present a gap rather than serve as a well needed mender of problems through articulate communication. I do believe there are many problems that are now and have in the past perplexed mankind. To solve these problems, we must accurately think and exchange the knowledge from one person's brain to another's through the means of talking. Let us insure that we do not merely wear out words. Let us use them in a meaningful manner that will get results so that we realistically accomplish that which we set out to do.

The reason I have strayed from my main thoughts is that I feel priorities must be evaluated again. We are an intelligent nation, as well as an affluent one. I do not for one moment wish to promulgate the impression that defense spending is not important, or that we should not remain defensively strong. What I do ask is that we ask ourselves the question, which comes first? Do we intelligently and sincerely ask ourselves how do we accomplish both? There is a way, yet we must find it. We must strike this happy medium and not sacrifice one priority completely for another priority. We must reason intelligently enough to look in all directions, not only in one.

So in closing, let us live upon this earth with dignity, help us to walk. We are spending billions of dollars each year. Just imagine what one of these millions could do to help M.S. victims.

Is my case of Multiple Sclerosis unique? I am crippled from the waist down. This I can accept. Will someone help me to at least experience what I would consider a luxury. The luxury I wish to have would be to sit in my wheelchair so that I could move about my home, around my yard, or ride in my car with my family.

The problem is that M.S. brought along a byproduct of the disease known as decubitis ulcers, which result from being in the same position of my body for long periods of time without being able to reposition or get up for awhile. As a result, pressure builds up and eventually cuts off the much required flow of blood to the derma cells. This is in conjunction with the problem, for example, in the sacrum area of such bone prominences, sharp points, such as the ilium bone. These pressing upon the exact same portion of the body, eventually cut off the blood flow. The constant uninterrupted pressure of bone prominences on the same part of the body causes necrosis, which is the actual dying off of the cells due to these

points mentioned. The decubiti ultimately develop an ulcer, a break through in the dermis which spikes fever, becomes necrotic, and requires the removal of this bad dermis through the medical process of debridement, which is removal of dermis in the area where decubitis ulcers have formed, and required nursing care.

This means I spend the greatest percentage of each day in my "water bed," which prevents decubitis ulcers. I say this "water bed" is truly the answer to my wish. I say thanks again for the Veteran's Administration who has permitted me to have this "water bed" in my home. It has made my life so much happier. Now, each day I have my wife and my three young, wonderful sons with me. My outlook has improved over 100 percent. I must also report that a special "flote" pad for my wheelchair has been developed, and I am now able to sit up as long as I wish without the problem of breakdowns or decubiti. Thanks to Dr. Barry Davidson, and Dr. Weinstein, developers of the water bed and flote pad.

A company named De-Puy Manufacturing Company, Inc., of P. O. Box 988, Warsaw, Indiana, manufactures this "water bed" and "flote" wheelchair pad. Undoubtedly, at one time or another, we have need for some type of orthopedic equipment. De-Puy is one of the largest and oldest firms of this type. Keep its address handy. Let's hope not, but some day you may have use for one of their products which would make your living a lot easier. When you do, just ask for Mr. Joseph Spiro, the Production Control Manager, or Mr. Robert Yates, their area Sales Representative. I make specific mention of these two gentlemen because of their cooperation, kindness, and understanding of my problem, and their assistance in obtaining my "Flote-Pad" and "Water-Bed." I could never truly express my gratitude. I have a complete detailed description of the scientific basis of these two products. Should you wish to learn their principle, just let me know.

I believe there is a theory in medicine known as the Milieu Theory, which in essence suggests that it is advantageous to any patient, that is patients who have experienced long periods of hospitalization, to periodically be changed from one room or area to a different one. A varying of environmental scenery proves to be tremendously healthy therapy for the patient's mind; his outlook also changes; his emotions and goods are of a winning type rather than defeatist and apathy.

AN M.S. VICTIM'S CONCEPT ON THE CAUSE OF M.S.

Scientists cannot detect any type of micro-organism which is capable of strange unheard of phenomena. As an average individual with no professional medical training, I am of the opinion that M.S. patients are being attacked by an unknown species or strain of Virus which is thoroughly confusing to our scientists, and has proven thoroughly capable of continuously evading being detected. Thus far, after many years of research, scientists still have no completely sound idea as to what this virus may be. Even Virology is at a standstill regarding M.S. The latest giant achievements in research in biology still make no mention of the probability of M.S. having a chance of profiting by their achievements. I refer to Professor Luria, recent winner of the Nobel Prize in Medicine. Without any doubt, Professor Luria's discovery in viruses is a significant advance to all medicine. The determining of the molecular structure of the genes, DNA, again is an advance of gigantic importance. New findings about our inner workings of cells can offer hope that scientists may end many diseases.

Is it possible that many of these extremely difficult degenerative type diseases could be the result of chromosomal damage, perhaps the failure of an enzyme to perform its intended function on schedule and completely. M.S.—is it a Virus which invades the nucleus and ruins our entire cell process? Such questions—many theories; to date no conclusive answers. The answer may just be the need of more money grants for more concentrated application of medical scientists' theories.

My opinion is that this Virus is so enigmatic that we cannot comprehend its incredible capabilities—like the dormant, sedate "fire dragon" that I make mention of in my book. I do firmly believe that this Virus has escaped all laboratory tests, tests of all types. Why is this? Could anyone detect a Virus if it were to be, let us say, nonexistent at the time you are in search of it?

Keeping in mind that we are dealing with an unknown, my theories can neither be labeled correct nor incorrect; yet it would behoove us to read on. It may be food for thought. This unknown Virus uses the human being's body as its dwelling place to harbor this unknown Virus. I do believe it is such in its composition that the spore is capable of dying and disappearing; yet not death in the exact meaning of the word. We must bear in mind that as long as its abode

or place of dwelling, the human body, is alive then it could be capable of such an unheard of action. The human body provides it with the necessary elements to bring it back to life, yet also to feed it enough of whatever it thrives upon or whatever it needs to regain life. When something triggers it off, that it must, referring to the Virus or spore, come back to life. It comes back as the seething mad "fire dragon."

As we all know, there is a group of lizards called Chameleons. They have a capability of changing the pigmentation or color of their body to exactly the same color of whatever it lands or settles upon. In this way, it is undetectable and extremely well concealed.

Bearing in mind that the Chameleon changes color not only due to its surroundings, but more importantly and most fascinating, it changes its color when it becomes subject to a particular mood. This seems difficult for me to comprehend—subject to a mood. Is this indicative of anything of medical significance? Wow! What a nervous system.

I am of the belief that this is the type of unknown we are dealing with. A virus actually capable of becoming extinct for various amounts of time and during this time the human body never rids itself of it because the antigens, and antibodies, and lymphocytes, do not know where it is. Therefore, the body itself cannot fight against this micro-organism that is supposedly extinct. How small is small? Even at this stage of research wherein we now employ the use of electron microscopes. In how many numerous sections of the human body could this unknown virus, temporarily extinct, be dwelling?

I am aware that in using the word extinct and then to continue to say it has the capability of reappearing is paradoxical. It is like saying a human being believes in reincarnation. Yet hold tenaciously in mind that we must reach out actually to theorems which appear to be at the brink of absurdity. Again, I say if we have laboratory tests which are capable of rendering more intelligent, down-to-earth evidence that medical science is now on at least the right road in detecting this dreadful crippler, then you may quickly scrap my theory, or better still, my purely hypothetical ideas.

I have read about the theory that M.S. is, to what degree I dare not state, the result that the Multiple Sclerosis victim's body has built up what I believe is medically termed to be an autoimmunity, in other words, the body itself wages war from within, allows the unknown crippler M.S. to continue to outsmart mankind. It could be like saying the white corpuscles (lymphocytes) do not wish to fight infection of the human body any longer. A certain part of the human body has developed a resistance against anything that ordinarily would be beneficial to curing its disease.

I spoke about the numerous sections of the human body in which this unknown Virus, if it is a Virus, is able to conceal itself. Truthfully, if I were this Virus, which to date has never been separated, or even detected, I think I would select what I refer to as the jungle of the human body—this being the nervous system. Just ponder for one moment on the composition of our nervous system. It is comprised of the central nervous system, the autonomic nervous system, the sympathetic nervous system, and the para-sympathetic nervous system, plus the spinal column, the brain along with their neurons, axons, synapses, and dendrites.

If I were the virus, I would say let the medical scientists find me in here, the jungle of the human body. I imagine to research the human nervous system with the determination to find a cause of a disease like Multiple Sclerosis would be like looking for a pin point on the overwhelming gigantic network of wires in a computer. Yet being realistic, is it not true that our nervous system is composed of a myriad number of fibers, thick, thin, long, and short?

Since most theories direct themselves to the idea that the unknown virus feeds upon the myelin substance of all nerve fibers, then it appears the unknown virus could in more probability than not exist here. This virus could lie dormant completed sedated until either its abode, the human body, provokes it through, as an example, a fall, overfatigue, extreme mental anxiety or worry, or the nervousness of everyday stress and strains. The other reason to trigger or provoke the virus could be the time element at which it is forced to erupt, for only God knows what real reasons. It could be it does need some of our body's oxygen, nerve fibre chemical substance, tissue, or fluids, chromosomes, enzymes. Take your pick—our body has much to offer. But the reaction when this Multiple Sclerosis cause is awake is horrifying. Is this virus the result of a chemical behavioral pattern which develops this virus from within the human body? Are we looking for the cause to be an invader? For example, the cause of a particular Flu Epidemic or other germ? Or is it due to a chemical imbalance in our body's chemistry?

HOW MUCH SHOULD M.S. VICTIMS KNOW ABOUT M.S.?

I believe that subsequent to diagnosing a patient as having Multiple Sclerosis, is the telling him that some day, or perhaps never, he or she may be crippled for life. I speak from personal experience. This is difficult to accept, and is sufficient medical information for any person to carry home and digest at one time. I was examined and treated by a number of doctors, as well as chiropractors. I held tenaciously to hope in finding out why I suddenly began to experience various feelings physiologically and noted various difficulties that I knew were abnormal to the human body.

Subsequent to the tingling feeling in my left hand, then the scotoma in my left eye, I was physiologically as good as new for approximately two years. Then, when I jumped over an open pipe trench hole and fell into the hole twisting my body like a pretzel as I fell, for I was carrying my briefcase in one hand and a suit in the other, the imbalance of weight as I was falling spun my body into a pretzel. I thought nothing of it until the following day. I was flying from Nantucket Island, Massachusetts to our home in South Burlington, Vermont. It was at this time that I placed a cigarette in my left hand. The cigarette rolled or fell out of my left and I was unaware of it. (Since then, I have quite smoking.) This is where it all started. In explaining this to my family doctor, he immediately knew the problem was neurological and recommended I visit a neurologist. He was absolutely correct. Multiple Sclerosis still had not yet overtly manifested itself. It took its time. Stage by stage my walking became affected. The right leg first. (Was the fall the trigger which provoke the progression of M.S. the dormant, sedate fire dragon?)

Keeping in mind that all through this ordeal to find out what was wrong, I never thought I would eventually become cripple. Such terrifying news to receive! Just think for a moment if you will how one's mind reacts when he or she is told, "You have Multiple Sclerosis". M.S. is a crippler, but M.S. is not in every case a crippler. Who knows how it will act on different people's bodies? No one knows because the paths it follows are quite erratic. Although in the greatest number of cases M.S. does cripple its victim, not knowing how much more time you have to walk, to stand, is very nerve-racking. But never despair. God gives all an inner strength. We hold this inner strength in reserve to call upon for such unfortunate and distasteful happenings such as M.S.

I believe the neurologist should provide the M.S. patient with all the possibilities that he or she may some day confront. It is better to know than not to know, and undergo sufferings you might possibly avoid had you only been informed what could occur in the future. Below is a list of hints to aid all M.S. patients:

1. A realistic resignation to the inescapable fact that one has M.S.
2. In accepting M.S. you unknowingly brace yourself against any other side effects to which we are prone.
3. If you are still capable of walking even short distances, or able to stand if it be only on one leg, keep this in mind: Never get overtired; when you are tired, rest. Stop whatever you are doing. Never push yourself. It is not good for you and allows M.S. to get a stronger hold on your body.
4. Get sufficient rest and eat well-balanced meals.
5. Take one vitamin a day to insure that your body receives its proper nutrients.
6. Keep in contact with your doctor and follow his recommendations. Report any new symptoms you may experience.
7. Keep occupied. A healthy mind in as occupied mind, an unoccupied mind is a place for the devil to lurk with worries, fears, and phobias.
8. If you are in a wheelchair, although I may sound entirely self-contradictory, it really isn't that bad. This you will have to experience—hopefully not for yourself. Just read item Number 1 over again. I say this because in retrospect, I recall the days which now I see were truly an ordeal in every sense of the word. I literally went through hell right here on earth, fighting with every ounce of energy I possessed to stand, to walk straight, to walk in any manner, to walk with the aid of one cane, then to walk with the aid of two canes, then to crutches, then to the most unwanted, yet most sensible mode of getting about, the wheelchair. It took me awhile to become adjusted to it, but there are plenty of people who are living in a manner they do not wish to; yet they do because they must. Some of us have no other choice. Let us smile and live happily; let us not cry and cry alone.

9. As I previously suggested, if you are in a wheelchair, obtain a Flote Wheelchair Pad. They are great for comfort and permit you to sit in the same position for extended periods of time without repositioning.

10. If you enjoy spending more time in your wheelchair than in bed, which is obvious, then you should occasionally have someone lift your legs and rest them upon another chair or hassock in order to help the circulation of blood in your legs. Circulation is important, especially where we are not able to exercise. By doing this, you prevent problems. It is easier to prevent than to cure.

11. If you smoke cigarettes or any form of tobacco—QUIT! Let common sense dictate. Because of our being inactive physically, our lungs are not exercised enough. If you smoke, as you inhale the smoke, you always leave a residual amount of smoke in the lower lobes of your lungs. As it remains and builds up, it can cause you a major problem. I quit smoking to help myself win my battle; you quit to help win your battle.

12. Keep an eye on the color of your urine (not in examining for diabetes), unless you have diabetes. M.S. could create a urinary tract or kidney infection, or bladder infection. Heavily colored urine with sedimentation is a sign that you may be harboring a possible kidney or bladder infection. It is highly advisable to frequently force liquids. Drink plenty of water, for this is easily flushed through the kidneys and bladder. Drink at least eight glasses of water each day. Occasionally, take note of your intake of fluids as compared to the output of liquids. It does not necessarily mean that if your intake is eight glasses of water or other fluids that your output must be exactly the same. A large discrepancy may be indicative of a problem. If this be the case, your symptom will be either a spiking fever or a temperature. As you know, for most people a body temperature of 98.6 degrees is normal; yet others might well be conditioned to slightly lower or higher grade temperatures. Your doctor will advise you on this point.

13. If you are a paraplegic, remember to constantly examine your lower extremities. If you cannot do this, have your visiting nurse periodically check for any possible injuries or infections to them. For the fact is, you could injure yourself due to lack of feeling and not be aware of it.

14. Safety—Always have safety foremost in your mind. You understand well your capabilities as well as your limitations. Always be in a position to contact somebody for help in the event of any unforeseen emergency. Let your neighbors know of your condition. Although you are certain they know and are very cooperative with you, have or devise certain signals which, when displayed, tell your neighbors that you are alone and need assistance. I can think of many, but you set up those which are best suited to your surroundings. Most paraplegics live in one-story homes which have ramps for ingress and egress, and the home layout is intelligently arranged according to the needs of the paraplegic. Just keep in mind that M.S. does not affect your mind; so use your own ingenuity.

15. Be as self-reliant as you possibly can. Try not to have others do for you that which you are capable of doing yourself. Use discretion. Test yourself first when you try a task before you plunge ahead and do it. If your test indicates truthfully you can do it without asking for help, by all means do it. If you have a doubt, and can see a possible accident, by all means ask for help.

16. Physical therapy is extremely vital and beneficial to M.S. patients. It aids enormously in the effects of spasticity and rigidity. A physical therapist really helps you to keep your muscles in tone. They prevent atrophy, that is, flabby muscles due to lack of use or exercise. This is how we keep the parts of our body in shape since we cannot move or exercise. Take advantage of physical therapy.

17. Occupational therapy is usually recommended for patients who experience long periods of confinement or inactivity. It is intended to keep one's mind occupied and their mental outlook healthy and in high spirits. It also helps patients who have difficulty with their hands. Occupational therapy should consider some factors before a particular type of therapy is prescribed for a patient. For example, if a patient's hands function well and are not impaired, the therapy would be intended to keep the patient's mind occupied, to pass time, and to keep the patient's mental outlook healthy. I had an experience in a hospital in which I spent six consecutive months because of decubitus ulcers. This particular medical problem requires extreme amounts of time, medical and nursing care, and just simply waiting for skin breakthroughs to heal. At the time, I was reviewing a book entitled, "Fundamental Laws or Thermodynamics," a book which I borrowed from my neighbor who is an electronics engineer. As I was reading various

laws of physics, a person with a nursing uniform on and a patch on her sleeve which read occupational therapist entered my room and nicely explained that I had been listed to do O.T. which consisted of knitting a pair of booties. The material was all brought in a little brown bag. I refused to comply, and graciously explained that I was doing quite well in the area of keeping my mind occupied; first by extensive reading, second by praying like hell to get better to go home to my wife and three young sons. The point is, the doctor from the physical medicine should take into consideration some of the individual's background before prescribing a specific therapy. Naturally, every case is a case within itself. As a result, the Physical Medicine Department doctors should show the patients some consideration. Not that I profess to be a scholar. Yet, I would dare say to make a pair of booties would be more disparaging and render a feeling of greater incompetency, rather than to lift my mental outlook. The aforementioned statement is my personal opinion. I should think age would also be a factor to consider.

TEN MEN IN A ROW

I have titled the final chapter in my small, yet hopefully interesting, book relating to Multiple Sclerosis and the indescribable urgency that exists to find the cause and cure for M.S., "Ten Men in a Row." In this chapter, I shall endeavor to truthfully and completely in the briefest way I know, depict for the reader as vividly and poignantly the true effects that M.S. is capable of. I am a victim of Multiple Sclerosis. I experience one and perhaps more than one of the symptoms or terrifying, destructive effects that Multiple Sclerosis does in spoiling lives. You, the reader, will be presented with ten men labeled by number only. Each of these ten men have the disease Multiple Sclerosis. To each man I shall assign only one of the difficulties of the disease; yet, bear in mind, that each man is unfortunate enough to have more than one of these effects of M.S. at the same time. Bear in mind also, that some men may experience only one medical difficulty as a result of M.S., and this could be in a minor form. You be the judge. Let us move one.

Quite basically, the connotation of Multiple Sclerosis is that the disease strikes more than one physiological function of the human body. It strikes more than one function, and its effects in most cases are permanent. It can strike and ruin the normal functioning of an organ or organs in the same person. Multiple Sclerosis is predominately associated with the horrendous feat of being a crippler as if this were not damaging enough.

Ten Men in a Row

Man Number 1.—Never again to walk or stand. A cripple.

Man Number 2.—Never again to experience the basic inherent drive, a God-given pleasurable function—sex. What a most difficult thought, and in this case true fact. Man Number 2 is 33 years of age, and married. I could expound for chapters on this score in itself. What would you do if this were to happen to you? It is a problem of immeasurable magnitude. Yet the majority of doctors when they hear you have M.S. easily say, "There's nothing that we can do."

Man Number 3.—Total loss of bladder control. Complete incontinence. What a depressing feeling to be abnormal. Yet again, there is nothing that can be done according to most doctors. A real spoiler of life.

Man Number 4.—Loss of normal bowel function. Again, a most depressing feeling to live with.

Man Number 5.—Loss of function of arms. What can one do without them?

Man Number 6.—Loss of functions of hands and fingers.

Man Number 7.—Possible loss of eyesight—blindness.

Man Number 8.—Loss of ability to talk.

Man Number 9.—Loss of function of feet.

Man Number 10.—The above listed nine points could never leave a man or woman more troubled. I shall not list a man Number 10. I leave this space for the hopeful cure that someday in the immediate future I can enter the name of a medical man or scientist who will erase the deprivers and spoilers of young adults. I hope I have reached someone who will truly recognize our need for help.

We need it now. Let's not wait any longer. We can do it if we all apply ourselves, as I have already explained. In the meantime, all victims of M.S., I salute you for I know what it is like to live with this monstrous, beastly crippler. Be sure you talk it up. We can stir help for ourselves. We must, otherwise, we shall continue to go on existing, not living. I am with you! Let's act now for action to cure multiple sclerosis!

STATEMENT OF BARRY CORBETT

Mr. CORBETT. Mr. Chairman and members of the subcommittee my name is Barry Corbett. I am presently the State Jaycee chairman for the Massachusetts Jaycee Multiple Sclerosis Campaign. I would like to tell you the Jaycee story on multiple sclerosis.

As you know, a former Attleboro Jaycee and now a multiple sclerosis patient, Robert Baptiste, approached the Attleboro Jaycees in September of 1971, asking for their help in the fight to combat multiple sclerosis. The Attleboro Jaycees felt that the best way they could contribute to the multiple sclerosis plight was to involve the people through a public awareness program and to propose this program to the Massachusetts Jaycees, which was unanimously accepted in November of 1971. At that time, I was appointed the multiple sclerosis State chairman. In March of 1972, I traveled to Tulsa, Okla., with the Massachusetts State Jaycee president and the U.S. Jaycee directors to present this program at the national jaycee board meeting with the hopes of it being adopted as a national program. The result was a complete success, labeling it as a priority health program on a national level. Presently, 6,400 multiple sclerosis program kits are being printed and will be distributed to all local chapters in the United States, having a total of 340,000 members. The national kick-off will be in June at the Jaycee National Convention in Atlanta, Ga.

I would like to quickly tell you about the proposal. The title of our program is the Bill Brownfield National Commission on Multiple Sclerosis. To clarify that, Bill Brownfield was the author of our Jaycee creed who died February 1971 with multiple sclerosis.

We found that we had to associate ourselves with this disease to really get it across and this is how we did it. The proposal is to commit ourselves to this program and to support legislation calling for the appointment of the national commission that will bring congressional awareness to the problems of research in this dread disease and to initiate the public awareness program throughout the whole country, the 50 State Jaycee organizations and through all the chapters.

Last but not least, the reasons for our proposals and why we are sincerely interested in getting something done. Bill Brownfield, as I mentioned was the author of the Jaycee creed, died from it. We are adopting this proposal in his memory.

Multiple sclerosis is the greatcrippler of young adults. A person afflicted with MS is between 20 and 40. More emphasis and funds from the Federal Government is needed in finding causes and cures of multiple sclerosis.

The last sentence in this documentary I was not going to include, but it is definite now. Very little has been done on the Federal level in this area. To sustain the American people from the economic loss incurred by this disease afflicting young people.

Miss Lawry just mentioned in her testimony that the Federal Government loses about \$2 billion in revenue a year. I wonder if it is going to take \$2 billion to find a cure for MS, for the half million people afflicted with that and related diseases and the half million to come.

Multiple sclerosis affects the age group where the individual has had no opportunity to create reserves against sickness and adversity. Finally, no age group is more deserving of the aid it solicits from this country, for no other age group has given so much in the defense of its country.

One final remark, I might add, is that our Jaycee creed in the last sentence says, "Service to humanity is the best work of life." That is why we are all here. On this final remark I would like to bring out that we have a definite, visible need for the commission to attract new research scientists, to attract new research initiatives, not only in the public but also in the private sector.

Thank you very much, Mr. Chairman.

Mr. ROGERS. Thank you, Mr. Corbett and Mr. Baptiste. The committee is very much impressed with your efforts, with what you have done and with your sincere testimony.

It is most helpful to the committee. We are grateful to you for what you have done in bringing this to the attention of the Congress through Congresswoman Heckler and for your presence today. It is most helpful.

Mr. Nelsen?

Mr. NELSEN. On Thursday night and Saturday night I have two commencement speeches in my district. So, last night I spent several hours, up until midnight, trying to search for an idea.

Mr. Baptiste, your statement that everyone in his lifetime should contribute something and without that his life would not be complete, that is a good commencement speech. I want to thank you for coming here.

You have suffered a severe disease and have come here to testify. Yet we see all around us those who following some affliction or some hard times who have given up and feel that somehow or another there is nothing worthwhile, yet, here you are with your young companion appearing before a committee of Congress of the United States.

I want you to go home feeling that you are appreciated and what you have said has made an impression on all of us. I want to thank you.

Mr. BAPTISTE. Thank you.

Mr. CORBETT. Thank you, also.

Mr. ROGERS. Dr. Carter?

Mr. CARTER. I have no comments other than to compliment the gentlemen on their presentation.

Mr. ROGERS. Mr. Preyer?

Mr. PREYER. I think Mr. Nelsen and the chairman have expressed our feelings about your testimony. I wish you luck, and thank you for your contribution.

Mr. BAPTISTE. Thank you very much for your kind words. Thank you for having us here. Mr. Nelson, God bless you. God bless you all. Thank you.

Mr. ROGERS. An unscheduled witness is here, Mr. Jacoby. We would be pleased to hear you. If you could just give us a few sentences, we are grateful to you for coming here.

Even though you are not scheduled, the committee would be pleased to have a quick statement from you. If you could identify yourself for the record, that will be fine.

STATEMENT OF ROBERT JACOBY, SILVER SPRING, MD.

Mr. JACOBY. My name is Robert Jacoby. As I was listening to what people were saying here, what was going through my mind was why does MS deserve particular attention over any other particular illness?

I have many friends in wheelchairs, traumatic paraplegics, boys and girls who drive alone in a car, who are also right in the middle of the fruits of their lives in their twenties who are paralyzed just as Governor Wallace is after being shot down last week.

Why does MS deserve particular attention over, for example polio victims? What is so different about multiple sclerosis? As I see it, the big difference with MS is that it is a continuing illness.

In my own case, I am talking but a year from now, I may not be talking. If the temperature, God forbid it, ever goes up in this room suddenly, I can't talk. Three years ago I was legally blind. Today my vision is pretty good.

Tomorrow, I have no idea. It is so innervating and so discouraging to know that the illness cannot be arrested. I personally would consider it a cure if a doctor said, "Jacoby, you will not get any worse." The other word I wish to emphasize is "hope."

That is a beautiful word, "hope." I think that all of us, for whatever reason, with or without illness, need hope to exist in our lifetime. As far as MS or any other illness for that matter is concerned, life cannot really go on without hope.

I just wish to emphasize the necessity of hope. Frankly, I think if you don't take action in setting up this commission in large measure you will be eliminating hope from a lot of MS patients.

Mr. ROGERS. Thank you very much, Mr. Jacoby, for an excellent statement. I hope this committee can respond appropriately to your plea.

Mr. JACOBY. Thank you.

Mr. ROGERS. Mr. Nelsen?

Mr. NELSEN. I have no questions. I thank you for an excellent statement.

Mr. ROGERS. Mr. Preyer?

Mr. PREYER. I thank you for a magnificent statement.

Mr. ROGERS. Dr. Carter?

Mr. CARTER. It has been said that yesterday is but a dream, tomorrow is but a vision. Perhaps by working today to give you hope we can make your dreams of yesterday not as bad and your visions of tomorrow—your visions of hope. We want to do that.

Mr. JACOBY. I thank you and my children thank you.

Mr. ROGERS. We thank all of you for being here. This concludes the hearings for multiple sclerosis. Thank you for being here.

(The following letters were received for the record:)

MANSFIELD, MASS., July 26, 1971.

HON. MARGARET M. HECKLER,
U.S. House of Representatives,
Washington, D.C.

DEAR MRS. HECKLER: I need your help. I am thirty-eight years old, the father of three lovely daughters, a registered voter in Massachusetts for the past seventeen years, a businessman, a former 5 handicap golfer, and a victim of Multiple Sclerosis. I need your help, and the help of your fellow legislators, to obtain sufficient funds for the National Multiple Sclerosis Research Society.

In recent weeks the most significant breakthrough in finding a potential cure for M.S. has occurred. I will be one of those select few, some might even call us "guinea pigs," who will test the effects of this newly discovered medicine. I do this only with the hope, the prayer, and the conviction that with sufficient support someone will discover a cure for Multiple Sclerosis and that this cure will allow me to live a normal life.

It becomes extremely discouraging for me to read of the millions which our government is granting to foreign nations, when there are over 500,000 Americans including myself, who are being deprived of their right to a normal life because our government has not allocated sufficient funds to support the research into a cure for M.S. Approximately 2,000,000 American family members are personally involved with its heavy economic burdens.

As a businessman it is embarrassing and frustrating to fall flat on a public street or in front of customers in my store, or to slur my words when I am taking an order over the telephone. How do I explain to my customers that I am not intoxicated from over-indulging in alcohol but my muscles and nerve controls are intoxicated by a disease which is incurable—at this time. Much more important, how do I explain to my three-year-old daughter, who is too young to understand, why I am different from her friends' fathers, why I cannot play with her or even pick her up and carry her.

I need your help; all who are afflicted with M.S. need your help, and with the rapid spread of this dreaded disease the future generations of this country need your help. Please help us to gain more funds for research.

I may never play sub-par golf again but I would be overwhelmingly thankful and gratified to be able to walk unaided down the aisle on each of my daughters' wedding days. This will be done if we can gain more dollars to fight M.S.

Sincerely and respectfully,

ROBERT BAPTISTE.

CONCORD MEDICAL CENTER,
Concord, Mass., May 31, 1972.

HON. HARLEY O. STAGGERS,
Chairman, Committee on Interstate and Foreign Commerce, U.S. House of Representatives, Washington, D.C.

MR. CHAIRMAN: My name is Dr. Edward Graham Toomey, I am a specialist in the field of internal medicine in private practice in Concord, Massachusetts; in addition, I am a physician to the Harvard University Health Services in Cambridge, Massachusetts. My private practice of medicine has included treatment of a substantial number of patients with multiple sclerosis, approximately twenty-five patients with this disease over a five year period since entering the private practice of medicine.

Multiple sclerosis, one of the most prevalent of nervous system diseases, often striking in the prime of youth, exacts a large annual toll of disability, mental deterioration and death among persons of both sexes throughout the world. Its cause, still unknown after a century of recognition of the disorder, has been termed the most urgent problem of basic neurology and one of the most obscure problems in the whole field of pathology.

The disease appears to have a higher incidence in the northern latitudes of the American continent, the incidence and prevalence rates being three times higher in Boston and six times higher in Winnipeg than in New Orleans.

The average life expectancy after onset is twenty-one years. The national origin, economic and social status and urban or rural status appears to show no association with prevalence of multiple sclerosis. All recent studies of sex distribution have revealed a preponderance of females amounting to roughly sixty percent.

The age at onset may be from the first to the sixth decade but the bulk ($\frac{2}{3}$) of the cases have their onset between the ages of twenty and forty years. The peak of onset appears to be twenty-four years. The age at onset appears to have a mild influence on the subsequent type of course, since a chronic progressive course is rare (3%) when the onset appears before the age of twenty-five years, but less uncommon (24%) when the onset appears after the age of twenty-five.

Ninety percent of cases in the early stages of multiple sclerosis are characterized by a relapsing or waxing or waning course. In ten percent, symptoms progressed steadily from the start.

The interval (latent phase) between relapses varied greatly from case to case and in individual cases. Some patients, particularly early in the disease, may have four or five clear-cut episodes in a year; others may have a latent phase for twenty years or more.

Many references to possible etiologic factors in multiple sclerosis have been made in the medical literature. Research studies and investigations of the possible role of blood vessel obstruction, infection, allergy, metabolic factors and

psychological factors have led no closer to the solution of the problem, of course, of multiple sclerosis.

Numerous precipitating causes such as injury, including surgery, pregnancy, infections (especially upper respiratory) emotional factors, chilling, fatigue and exhaustion and associated allergic disorders have been investigated to a degree during the past fifteen years without conclusive results or correlations; more rigorous and controlled statistical investigation is necessary hopefully in investigations and researches in the near future.

Numerous medications have been prescribed for multiple sclerosis without significant consistent response—including cortisone, muscle relaxants, nicotinic acid, and vitamins B and C.

In my private practice of internal medicine much benefit has come to the patient with multiple sclerosis in the form of supportive symptomatic treatment. The problem of evaluating the effects of therapy in multiple sclerosis is made more difficult by the unpredictability of the natural course of the disease, the difficulty of precise diagnosis and the long periods of remission.

In summary, the sincere ministrations of the kindly physician have probably been, of all aspects of treatment, the most helpful to sufferers from this disease, and remains the long range foundation for assisting patients with multiple sclerosis along their rough and uneven path through life. In general, such patients are hopeful and respond unusually well to sympathetic interest, encouragement, and minor signs of improvement.

It seems inconceivable that the brilliant minds and powerful tools of science, which have already established a broad base of knowledge in this field, will not in the reasonably near future successfully probe the "central mystery" of multiple sclerosis to reach a solution for this basic and urgent problem in the field of neurology.

Thus it seems imperative to initiate a broad national effort to catalogue and crystallize the present state of our knowledge and ongoing research efforts regarding this disease. Such a study would be the vital means to determine the most productive avenues of approach toward finding causes, cures, and treatments for multiple sclerosis, including recommendations regarding the need for revision of existing legislation in this area, as well as, for enactment of new legislation. Coincident with the present state of maturity and development of our national researches in this disease.

Many heartfelt thanks for the opportunity to participate in these vital hearings in reference to H.R. 13978 introduced by the distinguished Congresswoman from Massachusetts, Mrs. Margaret Heckler.

Kindest regards and best wishes.

Respectfully,

EDWARD G. TOOMEY, M.D.

(Whereupon, at 10:45 the hearing was adjourned.)















