DOCUMENT RESUME

ED 272 823	CG 019 306

TITLE	Alzheimer's Disease: Burdens and Problems for Victims and Their Families. Hearing before the Select Committee on Aging. House of Representatives, Ninety-Ninth Congress, First Session (October 28, 1985, Elizabeth, NJ)
INSTITUTION	Congress of the U.S., Washington, D.C. House Select Committee on Aging.
REPORT NO	House-Comm-Pub-99-542
PUB DATE	86
NOTE	61p.
PUB TYPE	Legal/Legislative/Regulatory Materials (090)
EDRS PRICE	MF01/PC03 Plus Postage.
DESCRIPTORS	*Family Relationship; Financial Problems; Health Insurance; *Health Needs; Hearings; *Helping Relationship; *Individual Needs; *Research Needs
IDENTIFIERS	*Alzheimers Disease; *Caregivers; Congress 99th

ABSTRACT

This document presents witness testimonies from the Congressional hearing called to examine the problem of Alzheimer's disease. Opening statements are included from Congressmen Rinaldo, Courter, and Saxton, and from Tom Dunn, the mayor of Elizabeth, New Jersey where the hearing was held. J. Richard Goldstein, New Jersey State Commissioner of Health, discusses the efforts undertaken in New Jersey to address Alzheimer's disease. Witnesses desribing personal experiences with family members who had Alzheimer's disease include: (1) Harry Phillipson, the husband of an Alzheimer's victim; (2) Lonnie A. Wollin, director of the Alzheimer's Disease and Related Disorders Association; and (3) Susan W. Fell, president of the Alzheimer's Disease Fund of New Jersey. Carolyn Epstein, the assistant executive director of SAGE, a community-based agency providing social services to the elderly, calls for a coordinated care system for Alzheimer victims and caregivers. Phillip H. Pearlman, director of the Union County Division on Aging, discusses his division's present activities regarding Alzheimer's disease, the unmet needs, and future roles. Kenneth L. Davis, professor of psychiatry and pharmacology at Mount Sinai School of Medicine, discusses research on developing a drug treatment for Alzheimer's disease, and Murray Feldberg, the coordinator of the Alzheimer's Disease Project at the Veterans Administration Medical Center in Lyons, New Jersey, discusses his center's program for Alzheimer's disease patients. Materials submitted for the record are appended. (NB)

CG

ALZHEIMER'S DISEASE: BURDENS AND PROBLEMS FOR VICTIMS AND THEIR FAMILIES

HEARING

BEFORE THE

SELECT COMMITTEE ON AGING
HOUSE OF REPRESENTATIVES

NINETY-NINTH CONGRESS

FIRST SESSION

OCTOBER 28, 1985, ELIZABETH, NJ

Printed for the use of the Select Committee on Aging

Comm. Pub. No. 99-542

U.S. GOVERNMENT PRINTING OFFICE
56-328 O WASHINGTON : 1986

SELECT COMMITTEE ON AGING

EDWARD R. ROYBAL, California, *Chairman*

CLAUDE PEPPER, Florida
MARIO BIAGGI, New York
DON BONKER, Washington
THOMAS J. DOWNEY, New York
JAMES J. FLORIO, New Jersey
HAROLD E. FORD, Tennessee
WILLIAM J. HUGHES, New Jersey
MARILYN LLOYD, Tennessee
STAN LUNDINE, New York
MARY ROSE OAKAR, Ohio
THOMAS A. LUKEN, Ohio
BEVERLY B. BYRON, Maryland
DAN MICA, Florida
HENRY A. WAXMAN, California
MIKE SYNAR, Oklahoma
BUTLER DERRICK, South Carolina
BRUCE F. VENTO, Minnesota
BARNEY FRANK, Massachusetts
TOM LANTOS, California
RON WYDEN, Oregon
GEO. W. CROCKETT, Jr., Michigan
WILLIAM HILL BONER, Tennessee
IKE SKELTON, Missouri
DENNIS M. HERTEL, Michigan
ROBERT A. BORSKI, Pennsylvania
FREDERICK C. (RICK) BOUCHER, Virginia
BEN ERDREICH, Alabama
BUDDY MacKAY, Florida
HARRY M. REID, Nevada
NORMAN SISISKY, Virginia
ROBERT E. WISE, Jr., West Virginia
BILL RICHARDSON, New Mexico
HAROLD L. VOLKMER, Missouri
BART GORDON, Tennessee
THOMAS J. MANTON, New York
TOMMY F. ROBINSON, Arkansas
RICHARD H. STALLINGS, Idaho

MATTHEW J. RINALDO, New Jersey,
Ranking Minority Member
JOHN PAUL HAMMERSCHMIDT, Arkansas
RALPH REGULA, Ohio
NORMAN D. SHUMWAY, California
OLYMPIA J. SNOWE, Maine
JAMES M. JEFFORDS, Vermont
THOMAS J. TAUKE, Iowa
GEORGE C. WORTLEY, New York
JIM COURTER, New Jersey
CLAUDINE SCHNEIDER, Rhode Island
THOMAS J. RIDGE, Pennsylvania
JOHN McCAIN, Arizona
GEORGE W. GEKAS, Pennsylvania
MARK D. SILJANDER, Michigan
CHRISTOPHER H. SMITH, New Jersey
SHERWOOD L. BOEHLERT, New York
JIM SAXTON, New Jersey
HELEN DELICH BENTLEY, Maryland
JIM LIGHTFOOT, Iowa
HARRIS W. FAWELL, Illinois
JAN MEYERS, Kansas
BEN BLAZ, Guam
PATRICK L. SWINDALL, Georgia
PAUL B. HENRY, Michigan
JIM KOLBE, Arizona
BILL SCHUETTE, Michigan

Fernando Torres-Gil, *Staff Director*
Paul Schlegel, *Minority Staff Director*

CONTENTS

MEMBERS OPENING STATEMENTS

CHRONOLOGICAL LIST OF WITNESSES

APPENDIX

ALZHEIMER'S DISEASE: BURDENS AND PROBLEMS FOR VICTIMS AND THEIR FAMILIES

MONDAY, OCTOBER 28, 1985

House of Representatives,
Select Committee on Aging,
Elizabeth, NJ.

The committee met, pursuant to notice, at 9:30 a.m., in the Elizabeth City Council Chambers, Elizabeth, NJ, Hon. Matthew J. Rinaldo (acting chairman of the committee) presiding.

Members present: Representatives Rinaldo, Courter, and Saxton.

OPENING STATEMENT OF REPRESENTATIVE MATTHEW J. RINALDO

Mr. Rinaldo. Good morning. This hearing has been convened at my request to examine one of the most serious problems facing senior citizens today in our country, Alzheimer's disease. Before we begin, I want to thank two of my colleagues who are members of the Aging Committee for being with us this morning: Congressman Jim Saxton of the 13th District, and Congressman Jim Courter of the neighboring 12th District. I think their presence here shows their commitment to this crucial problem in American health care.

As the ranking minority member of the Aging Committee, I specifically requested this hearing today to bring attention to Alzheimer's disease. Alzheimer's disease has a devastating impact, not only on its victims, but on their relatives and loved ones. And the tragedy is, the United States still has not made the kind of commitment it must if we expect to overcome this disease. We do not know the cause. We cannot even be sure of the diagnosis. And we have no long-term health care policy or services to provide for the care of Alzheimer's patients.

Yet, Alzheimer's disease has an enormous impact on senior citizens, and on our health care system. Alzheimer's affects at least 2½ million persons in the United States, between 10 percent and 15 percent of the population over 60. Second, this illness is the leading cause of institutionalization among the elderly in America. It is responsible for as many as 650,000 people over 65 in nursing homes.

As revealing as these numbers are, the United States still has no viable long-term health care policy or method of repayment for the care of Alzheimer's patients.

I constantly receive letters from my constituents telling me of the personal hardship involved in caring for Alzheimer's patients. We need to review the overall strategy on how to win the war against this disease. We need to increase research funding to discover its cause, how to diagnose it, and most important, how to treat the disease. Right now, we are fighting in the dark.

Obviously we do not have the resources in the budget to drastically increase spending for Alzheimer's care and research immediately. Last year the Federal Government spent $56 million on Alzheimer's programs, compared to more than $1 billion for cancer research. I currently have legislation pending on the House floor that would provide money to States to increase their Alzheimer's programs. We need to employ the same weapons against Alzheimer's disease as we have against cancer and heart disease.

I know of the heartfelt devotion all our witnesses have to combating this deadly enemy. Susan Fell of the Alzheimer's Disease Fund of New Jersey is with us today, and is actively raising money to help fund much-needed respite care service such as the Adult Day Care Center at Memorial General Hospital in Union, and the COPSA Day Hospital in New Brunswick.

Lonnie Wollin is one of the founding members of the Alzheimer's Disease and Related Disorders Association and is in the battle zone helping families cope with a loved one who falls victim to this disease. Doctors Davis and Feldberg are diligently striving to find the cause, and ultimately the cure, for this medical nightmare.

I feel it is time for Congress to bring this issue to the forefront of our agenda. This hearing is just one of a series of hearings the Aging Committee has held on this issue, but we all must take a more active stand against this deadly disease, the Nation's fourth largest killer.

I would like to call on my colleagues for any opening statements they have. Congressman Courter?

STATEMENT OF REPRESENTATIVE JIM COURTER

Mr. COURTER. Thank you. I would like to thank Congressman Rinaldo for holding the hearing. He is the ranking minority Republican member of the Select Committee on Aging and has demonstrated a leadership in his compassion and concern for the ills that affect the elderly population of senior citizens in our country.

This is one of many hearings he has held over the course of the years, studying Alzheimer's disease and studying those concerns of the disease that affect senior citizens.

I would like to thank the very impressive array of panelists this morning. As Congressman Rinaldo indicated, it is a disease that affects a growing number of senior citizens, with the estimate varying from 7 to 10 percent of those about 65, going up to 20 to 25 percent of those that are 80 years of age.

The social and economic implications of the disease are a great deal of pain, and we have seen films depicting that pain, together with a great deal of suffering and disability, a tremendous amount of human and economic resources being devoted to the care and treatment of this type of disease.

The social costs of the personal catastrophe that is brought to the families of victims cannot be properly measured by anybody.

The economic cost of the disease has to some extent been assessed, and the numbers are dramatically significant and seem to be growing.

Congressman Rinaldo indicated we spend so little of our Nation's resources on this growing problem, and hearings like this allow the Nation's policymakers to focus their attention on the requirement of spending more resources on this type of problem.

I think the hearing today is particularly appropriate because November is National Alzheimer's Disease Awareness Month. It is my understanding that Governor Kean is planning a statewide conference on this topic, later on in November, and we welcome the attention that this particular disease is getting in the State of New Jersey as a whole.

Within the next 50 years, our senior citizen population is going to increase dramatically, with 20 percent of the population in the next 50 years being 54 years of age or older.

Too many of these people will have AD unless we find a cure and unless we find a treatment.

I can go on, but I don't think it is necessary. I think the important part of the hearing is to listen to witnesses.

I want to thank the witnesses for coming today and for the support of the people here today, I wish to congratulate the press for coming, because heightened awareness of this problem is very important.

Again, I want to thank Congressman Rinaldo for his leadership in this area. Thank you.

Mr. RINALDO. Thank you very much for coming. We appreciate the time that you and Congressman Saxton have taken to come here today.

Congressman Saxton, do you have any opening statement?

STATEMENT OF REPRESENTATIVE JIM SAXTON

Mr. SAXTON. Thank you. It is a pleasure to be here today. I want to say that I think it is particularly important we do this. As I was saying to Dr. Goldstein, we as Members of Congress deal with such a wide array of issues, that hearings like this give us an opportunity to understand in depth the real importance of what happens to those individuals who are afflicted by this disease and the families as well.

You might say that through the committee, I have learned a great deal about the disease. I have learned that financial costs of AD are staggering and the emotional toll is wrenching.

Alzheimer's disease is a progressive, irreversible neurological disorder characterized by a deterioration of cognitive functions such as memory, attention and judgment. The disease begins with simple forgetfulness followed by gradually noticable and then severe changes in memory and personality. The disease can run its course in a few years or may last as long as 15 years. Eventually the Alzheimer victim cannot care for himself, and life expectancy is usually reduced, by as much as 50 percent. Diagnosed first in 1906, by Alois Alzheimer, the cause of Alzheimer's disease is unknown at the present time.

It is the leading cause of institutionalization of the elderly; it accounts for as many as 50 percent of elderly in long-term health care settings. Total elderly institutionalized is 1.3 million.

It accounts for an estimated 50 to 75 percent of dementia in the elderly with the remaining fraction of dementia caused by arteriosclerosis, stroke-related diseases, and a score of treatable causes of dementia.

The estimates are that between 10 percent and 15 percent of the U.S. population over 60 have Alzheimer's disease.

It is responsible for 120,000 deaths in the United States annually, ranked as the Nation's fourth leading killer, behind heart disease, cancer and strokes.

And the risk increases with age. It strikes 5 to 7 percent of those over 65, but increases to 20 percent of those in their eighties.

The cost of treatment and long-term health care is estimated at $25 to $30 billion annually, $12 billion of which comes from Federal sources—Medicaid, $10.4 billion; Medicare, $0.4 billion; VA, $1.1 billion, et cetera.

By 1990, estimates are that costs to institutionalize and care for sufferers of Alzheimer's disease will reach $43 billion at the Federal level; by the year 2000, estimated 3 to 4 million Americans, 1 out of every 20 adults over 65 will be a victim.

The costs to the Government as well as individuals will increase with the graying of America. According to the Census Bureau, the number of Americans over the age of 65 doubled from 1950 to 1980, and is expected to double again by the year 2030, making 20 percent of the population 54 or older.

This frightening disease must remain a top national priority.

Finally, I would like to share with the committee the words of Dr. Michael Shanahansky of the New York College of Medicine. I read these words while studying Alzheimer's and I feel they strike the heart of the issue. He said, the failure to view aging of the brain as a pathological process, a disease, will turn victories in our crusades against cancer and heart disease into hollow shells and the fruits of such victories will be bitter ones, as we watch the wards of our hospitals filled with older people with strong bodies, but diminished minds.

Compassion must be shown for the victims and their families.

Thank you. I look forward to the testimony of the witnesses this morning.

Mr. RINALDO. Thank you.

I would like to call on Mayor Dunn to welcome our guests here today, and before the mayor speaks, I want to take the opportunity to thank the mayor and the Elizabeth City Council for the use of their chambers and the mayor's staff for their help with this hearing.

Mayor Dunn has always been very helpful to this committee. Whenever our committee has had a meeting in the city of Elizabeth, he has made the chamber available.

We appreciate his hospitality, cordiality and the use of the city chambers for the hearing.

STATEMENT OF THE HON. TOM DUNN, MAYOR, ELIZABETH, NJ

Mayor DUNN. Thank you, Mr. Chairman, and other distinguished Members of the Congress, Dr. Goldstein, Commissioner Goldstein, and my fellow citizens. This is a great way for me to start my week off, by welcoming each and every one of you to the city of Elizabeth, to the city council chambers, to participate in this most important business.

I warmly extend that welcome to each and every one of you, and we are indeed honored that this committee would single out the city of Elizabeth for the site of such an important meeting.

I would like to say that about 4 to 5 years ago, I had a lady call me up as I was hosting a radio show, who asked me to solicit funds over the air for the Alzheimer's Disease Foundation. Truthfully, I did not even know how to pronounce the word at the time. She made a reference to Rita Hayworth being a victim of it.

She sent me some literature. I found, to my dismay, that not only was I ignorant of Alzheimer's disease, but I found that many listeners to the radio program that I hosted each week were ignorant of it.

In a period of about 4 or 5 years, there is a new awarenesss to the terribleness of Alzheimer's disease.

It is gratifying to know that the Congress is showing greater concern for finding a cure and treatment of the disease than ever before.

You know, if you will allow me, gentlemen, to give an editorial opinion, from where I sit as mayor, and that is as an active political person, there is a concern in this country today, but I can only speak of my own jurisdiction, but that perhaps we are showing too much concern for a subject that is uppermost in our minds today, that of the victims of AIDS. While everybody has a compassion and a concern for those who are afflicted with AIDS, we have a fear that perhaps more attention will be shown to fighting that disease, say, than to some of the diseases that have been mentioned here before, cancer, heart disease, et cetera.

I had a concern or have a concern, too. I know the political picture. I know that those who scream the loudest, who get the attention of the press and media, seem to get more interest from our legislative bodies and from our political leaders.

We all know that cancer is a terrifying disease; we know that AIDS is a terrifying disease.

There should be a list of priorities as to where our Federal tax dollars should go. This priority list is an absolute must as far as I am concerned to make sure we spend our money in the right places.

I have a personal interest in worrying about our young children who suffer from leukemia and other forms of cancer. We want to make sure whatever moneys are available should be helping kids to grow and to survive as many of us have done.

Those of us in our sixties realize how fortunate we are compared to others that we lived with, associated with, in our long lifetimes.

We have a genuine interest in young people. We have a genuine interest in a very practical matter, making sure that the money is spent for the right purposes.

I can think of no more worthwhile purpose than spending the money to find a resolution to the terrifying Alzheimer's disease, as I heard described on telephone, the disease which has killed two people, not only a victim, but a person who must take care of that victim.

I welcome you. We are happy to have you. We are honored that you are here. We know that this is going to be a very, very productive meeting.

Again, thank you so much for singling out the city of Elizabeth for the site of such an important meeting. Thank you.

Mr. RINALDO. Thank you very much, Mayor.

We will begin with our first witness. I would like to ask all of the witnesses, if they would, when you are called on to testify, please limit your comments to 5 minutes.

You can submit the entire statement for the record. It will be included.

I would ask you to step up to a podium, so that everybody can hear the testimony.

Our first witness will be Dr. Goldstein.

Dr. Goldstein.

STATEMENT OF J. RICHARD GOLDSTEIN, M.D., NEW JERSEY STATE COMMISSIONER OF HEALTH

Dr. GOLDSTEIN. I appreciate this opportunity to inform your committee of the efforts we have undertaken in New Jersey to address this devastating disease.

Alzheimer's disease is a slowly progressive disease which may last anywhere between 2 and 20 years. There is no cure for the disease nor any specific treatment. This neurological disorder causes a gradual deterioration of the brain resulting in the victim's failure to communicate, ambulate, and control bodily functions and ultimately causes death.

Nationwide, it is estimated that as many as four million Americans have Alzheimer's disease or a related disorder. We estimate that approximately 230,000 residents of New Jersey suffer from cognitive impairment. Studies based on small samples indicate that 10 to 20 percent of the elderly with symptoms of dementia have reversible conditions. As many as 100 reversible conditions can present symptoms similar to dementia; depression, head injury, high fever, poor nutrition, adverse drug reaction, et cetera. Alzheimer's disease and multi-infarct dementia account for approximately 80 percent of the irreversible dementias. Other causes of irreversible dementia include Pick's disease, Huntington's disease, Parkinson's disease, Creutzfeldt-Jakob Disease, et cetera.

The role of caring for a victim of Alzheimer's disease at home is demanding and has been likened to a "36-hour day." One caregiver in New Jersey explained her exasperation in caring for a loved one as a malfunctioning mind enclosed in a functioning body. Despite careful explanations and simple directions, many victims of Alzheimer's disease are unable to carry out simple commands. Someone must constantly monitor the Alzheimer's victim's activity. That someone is the caregiver, who is usually a family member since most persons with Alzheimer's disease are cared for by their families at home.

Prevention of accidents affecting the victim and the immediate environment are of constant concern for the caregiver. The Alzheimer's victim may remember how to boil water, but forget to turn off the stove. The victim may wander outside and forget how to get home, become injured by falling down familiar stairsteps or walk in front of a moving car. Protecting a person from harming himself or others requires 1-on-1 care. The constant monitoring does not leave much personal time for the caregiver; this in turn leads to an increase in the level of stress for the caregiver.

Another stressful situation occurs as a result of financial burdens of Alzheimer's disease. The cost of care increases as the disease progresses. In the later stages, custodial services such as bathing, dressing and feeding are needed and are not covered by medical health insurance. Consequently, if the caregiver must continue to work, a paid helper must be hired and be paid by the victim or by the caregiver. Other noncovered expenses include respite care, day care services and medical-surgical supplies such as incontinence pads and diapers.

Recognizing the devastating impact Alzheimer's disease has on the victim and family, legislation was signed by Gov. Thomas Kean on September 29, 1983, creating the Alzheimer's Disease Study Commission. The commission, of which I am chairman, first met in July 1984. It was charged with the duties of evaluating the extent and severity of the incidence of the disease in New Jersey, the needs of the victims and their familes, and the availability and affordability of long-term care, home care or other alternatives to institutionalization. The Commission is also responsible for gathering and disseminating information about the care and treatment of persons with the disease to make health care professionals and members of government more aware and better informed about Alzheimer's disease. Findings of the commission will be reported to the Governor and the legislature, along with any legislative bills the commission finds appropriate in addressing the serious medical and social problems presented by this disease.

One of the first actions of the commission was to convene a series of three public hearings to which professionals and family caregivers were invited.

Obtaining an early diagnosis of Alzheimer's disease was identified as a major problem encountered by victims and their families. A diagnostic tool specific for Alzheimer's disease does not currently exist. Therefore, physicians treating clients with a suspected dementia work by a process of elimination. Many reversible conditions can mimic Alzheimer's disease and the ramifications of mislabeling a client can be catastrophic for all those involved.

Family caregivers and professionals alike expressed the need for a more informed medical community. Physicians responsible for providing a diagnosis should have knowledge of and access to those having the expertise and equipment necessary to adequately assess those individuals presenting the symptoms congruent with dementia.

At the time of the hearings, New Jersey did not have a diagnostic center designed to meet the needs of those affected by Alzheimer's disease. Family members reported traveling to Philadelphia, New York and Maryland in order to obtain a comprehensive diagnostic evaluation. It was recommended that the creation of one or more diagnostic centers in New Jersey would facilitate an earlier and more accurate diagnosis. Early diagnosis is essential to the effective and efficient long-range planning required by those affected by this disease. In addition, these diagnostic centers have the potential to provide a secondary gain of being established training sites for health care professionals, as well as correctly diagnose those that have treatable disorders.

Despite the burdens of caregiving the desire to keep the Alzheimer's disease victim at home for as long as possible was well affirmed by many providing testimony. Successful home care, however, can be draining and requires community resources which assist and support the primary care providers.

Unfortunately, many family caregivers and professionals are unfamiliar with the mechanism of receiving information about available community resources. Individuals are all too often passed from one potential information source to another without obtaining answers and/or help in identifying specific local resources.

Several viable suggestions were proposed by those providing testimony to help bridge this informational gap. Many participants thought that a statewide clearinghouse for information and referral would be beneficial. Likewise, improved dissemination of information pertinent to Alzheimer's disease and better utilization of the existent network serving the older population in New Jersey were suggested as perhaps the "best possible" resource for a standardized information and referral system.

A plea for improved availability of community-based services was also expressed by those testifying. The need for day care programs designed for Alzheimer's disease victims and other forms of in-home and/or institutional respite care for family care providers was clearly identified as a desirable community service. Most day care centers operate Monday through Friday between the hours of 9 a.m. to 4 p.m. Family care providers expressed the hope that new programs be developed to meet the needs of those care providers who must work. Effective day care has the potential to reap multiple benefits such as improved functional level, self-esteem and dignity for the victims and provide a period of rest or reprieve for stressed family caregivers.

Family caregivers were adamant about the need for improved education of both professional and nonprofessional individuals caring for victims of Alzheimer's disease. Physicians, nurses, social workers, therapists, clergy, homemaker-home health aides, and family care providers were specifically identified as priorities for improved education.

Physicians, it was reported, often lack knowledge about the disease, appropriate diagnostic workup, and the availability of community resources which may be of benefit to the client and/or the family.

Medical and nursing personnel in acute care hospitals and long-term care institutions, on numerous occasions, readily acknowledged to family members their lack of knowledge about Alzheimer's disease.

Likewise, during the home stage of care, which is desired by most for as long as feasible, nursing, and home health aides admittedly lacked training concerning specific interventions for the Alzheimer disease victim.

It was recommended that specific training related to the needs and health problems of the older adult should be mandated by the department of higher education and/or various disciplines. Furthermore, specific training about Alzheimer's disease should be required for those presently involved in the care of geriatric clients via continuing education programs throughout the health care system.

A problem identified by almost every individual providing testimony, both family caregivers and professionals alike, was the financial strains which Alzheimer's disease all too often inflicts on its victims and their families. The long-term effects of a chronic illness such as Alzheimer's disease requires, most often, support in terms of custodial care, social services, counseling, and support and respite for family care providers. Subsidized funding for the chronically ill individual who requires these services but does not require "skilled care" is currently non-existent for a large portion of the U.S. population.

Only those who are extremely wealthy or qualify for Medicaid can afford the necessary care to maintain the client at home or in an institution—that is, the 15,000 to 40,000 or more dollars per year needed to care for the Alzheimer's disease victim who, once diagnosed or exhibiting behavioral symptoms, generally has a life expectancy up to 10 years or greater.

One alternative is to apply for municipal welfare, an action providing additional trauma for many individuals and in the end financial aid still may be infeasible.

Professionals from long-term care institutions, home health agencies, and day care facilities shared the financial concern of family care providers. While their goal is to provide quality high level care, reimbursement constraints for "nonskilled" care makes admission of Alzheimer's victims a financially draining situation. One speaker recommended that it was time for the "arbitrary and restrictive" interpretation of the terminology "skilled" versus "custodial" care to be reassessed; current definitions of these terms and current policy disqualifies Alzheimer's victims from benefits from most private insurance plans and Medicare. Even Medicaid reimbursement is based on the level of "skill" required to care for the individual. Hence, those agencies accepting clients receiving Medicaid are reimbursed for the lower rate of "nonskilled" care despite the reality that specialized skill is required to care for the individual with Alzheimer's disease and his/her family.

Finally, choosing a desirable institution to provide for the multiple and specialized needs of the Alzheimer victims has been identified as a time consuming and frustrating process by many. Families are confronted with long waiting lists, institutions who have only a limited number of beds for confused individuals, and all too often, nursing homes who refuse to accept patients with dementia. Even if one finds a home which will accept an Alzheimer's disease victim, many institutions will not accept Medicaid clients. It was reported that some nursing homes in New Jersey will refuse to keep a client who has exhausted all of his/her private pay funds.

Support was also requested for the development of special units or programs designed to meet the specific needs of the Alzheimer's disease victims within existing nursing homes. Several programs currently exist in New Jersey long-term care institutions and may eventually serve as role models toward quality care.

As a result of the poignant testimony at these hearings, the commission adopted several recommendations:

One. The State of New Jersey should support the establishment of a statewide resource directory for family caregivers and health and human service providers.

Two. The State of New Jersey should develop an Alzheimer's disease and related disorder resource center which will link Alzheimer's victims and their families with appropriate programs and services to meet their complexity of needs.

Three. The State of New Jersey should support the establishment of a diagnostic center for the cognitively impaired.

Four. The State of New Jersey should provide support for the expansion of adult day care programs and should provide for and coordinate the utilization of existing services for both in-home and out-of-home respite care in order to furnish relief and support to family and other unpaid care providers of those afflicted with Alzheimer's disease or a related disorder.

Five. The State department of health in collaboration with the various health-related professional associations, the departments of community affairs and human services, and the Alzheimer's disease support network should develop and implement seminars and/or workshops on issues relevant to Alzheimer's disease and related disorders.

Six. The department of insurance should determine the feasibility of developing a long-term insurance package for persons with Alzheimer's disease.

Although the work of the commission has not concluded, the department of health has begun to implement these recommendations.

The department of health and the division on aging were successful in obtaining a grant from the Brookdale Foundation. These moneys will be used to fund the Governor's conference on Alzheimer's disease and related disorders which is scheduled for November 19, 1985, at the Hyatt Regency in Princeton. The gerontology program of the department and the division on aging are currently developing a resource directory which will be distributed at the conference.

The department of health will be awarding a contract of $500,000 to the University of Medicine and Dentistry, Rutgers Medical School CMHC to develop the Institute for Alzheimer's Disease and Related Disorders. The institute will include an Alzheimer's disease resource center as well as a diagnostic center. The resource center will have the responsibility to act as an information and referral clearinghouse, maintain a toll-free hotline, develop specialized educational materials, and provide technical assistance to support groups for caregivers of persons with Alzheimer's disease.

In addition, the institute will operate a diagnostic center for the cognitively impaired. This center will be available to all residents of the state and will offer a multidisciplinary approach to assessment. We believe it will facilitate effective and efficient long-range planning for the victim and family affected by Alzheimer's disease or a related dementia.

The department recently offered a conference on home management of the person with dementia. This conference was attended by approximately 200 persons. Additional training seminars for professionals will be offered this year by my department and the division on aging. While we can begin to address the training needs of health and aging professionals and family caregivers, adequate funds are not available to accomplish this goal in the most appropriate manner.

Legislation has been introduced in the assembly, A-3194, which would appropriate to the department $1 million for the purchase of adult day care services for individuals with dementia. We support this legislation and believe that day care may promote a better quality of life for the victim by maintaining an optimal level of functioning for a longer period of time.

We are proud of what we have accomplished in such a short period of time. We will continue our efforts to build a continuum of care for the victim and caregiver that is humane, affordable, and attainable.

In conclusion, I would like to share with you the experience one member of the commission had in obtaining an accurate diagnosis. After months of going from clinic to doctor, her husband was diagnosed as having Alzheimer's disease. She was told, "Just take him home and love him." She thought that meant that he would recover. She later found out that the diagnosis of Alzheimer's disease is a death sentence. Not a quick death sentence, but a slow, drawn-out ordeal for the victim, the spouse and for family and friends. It is our responsibility as public officials to see that other caregivers do not encounter this experience.

Thank you.

Mr. RINALDO. Mr. Phillipson.

STATEMENT OF HARRY PHILLIPSON, MAPLEWOOD, NJ

Mr. PHILLIPSON. I am Harry Phillipson, residing alone with my wife, Anna, at 50 Burroughs Way, in Maplewood, NJ. We have been married to each other for 60 years. I am a retired lawyer, having practiced in Newark for 50 years. I am 80; my wife, 81.

I shall present before this forum first my personal situation and needs, and then suggestions for consideration by this committee in aid of all Alzheimer victims and their families.

We have two children, a son and a daughter. My son is a professor of physics at University of Colorado at Boulder where he lives with his wife and children. My daughter, a teacher, resides with her husband in Fanwood, NJ, and is busy with their two children and grandchildren.

Anna, my wife, was an intelligent, articulate, and capable person, devoted to her home. She was a loving wife and mother and fully enjoyed our previous happy life together. A schoolteacher of excellence, she was a knowledgeable musician, especially skilled at the piano. Fortunately my personal health is good, notwithstanding my age.

Seven years ago Anna began to show signs of serious forgetfulness and unusual behavior. There were times even then when she did not know who I was, nor would she remember her own children and grandchildren. Her condition mentally became progressively worse, and she now exhibits all the symptoms of Alzheimer's disease. Besides not remembering members of her family, such as her four sisters and brother, she continues to wonder who I am, and has no recollection of our marriage in 1925, the happy times and experiences we shared over the years, the birth of our children and our rearing them to adulthood. She must be washed and dressed by me. When handed a toothbrush, she holds it and does not know what to do with it. When asked to put a knife and fork opposite each plate, she is confused and unable to perform. She does not know how to switch on a light. She is confused, does not know how to walk into the respective rooms in the house and I must lead her constantly. When, for example, she is called to the breakfast room for lunch or dinner, her response is usually, "Where is the breakfast room?"

While she has glaucoma and 20–50 vision, she is unable and refuses to attempt to read and is disinterested in television and unable to follow a program. While not yet incontinent, she must be led to the bathroom and told each time what to do. She forgets all matters almost immediately. She is unable to perform any cooking or household chores. Though she eats fairly well, she must be helped and guided in using the proper cutlery. No medication is permissible for she is allergic or sensitive to sedatives such as Dalmane, Valium, Librium, et cetera, which quickly bring on unusual hallucinations. Except for osteoarthritis, which gives her discomfort, her health is generally good. But her walking is difficult, slow and faltering. While using a cane, she relies on the added support of the various furniture, or I must hold her hand. She no longer can comprehend numbers, days, dates, or time. She cannot read a clock. She cannot make a choice, she requires direction and decisions of others.

Though she still loves to listen to music, no longer can she play the piano at which she was unusually skilled. She follows the music on the radio or recording, at times sings to herself and often chants children's songs. When she attempts to write, the words are unintelligible, she can sign her name, only with great difficulty. She has problems with her speech and mostly is unable to identify a person or a thing or to express her feelings and thoughts. When left to herself, she will at times put on wrong clothes, such as a nightgown over her dress, and so on. She talks constantly and incessantly, coining words that are unintelligible. She talks to objects in the room as persons. She will make a statement and treat it as though coming from another person, and then argue vociferously against the statement as though the imaginary person was wrong. She exhibits periods of frustration. At times she laughs and cries and at times she is obstreporous and stubborn, difficult and exasperating.

All sorts of neurological tests, including CAT scans, have been made. One eminent neurologist and neurosurgeon connected with the Mount Sinai Medical Center suggested a head operation to create a "shunt" which he felt reasonably sure would help. But a second opinion, from an equally eminent neurologist and neurosurgeon at the University of Medicine and Dentistry in Newark, was to the contrary. No operation was undertaken.

I am the sole caretaker, arising daily at 4 a.m. I do all house chores, cleaning, washing, shopping, and cooking. My son in Boulder can give me only spiritual support, but my daughter helps when she can find time away from her own home responsibilities and teaching; she is however, in daily touch with me and is most cooperative and helpful.

What are the needs of patients and their families?

One. It goes without much proof that in-home care is preferable to institutionalization. I have employed women to aid me at home; but all were useless to take care of an Alzheimer patient, for none had the special training and skill required. It is a difficult and trying field, but this special training should be given in schools that train persons to serve as nurses aids, so that a pool of these trained people would be available upon which to draw for help.

Two. Steps should be taken, if possible, to provide for Medicare and Blue Shield reimbursement for expenditures incurred by Alzheimer patients for their medical treatment; but medical treatment should include the broad medical care and expense necessary for the Alzheimer patient, whatever his or her needs have become. At present only patients under Medicaid are provided for to some extent. For Alzheimer patients, Medicare should give the same benefits as others have under Medicaid, because Alzheimer patients have become now a so-called special unfortunate class requiring special public help.

Three. For my wife, I shall do everything in my power to avoid institutionalization, first because at-home care is better for the patient, and then because I must also consider the monumental costs for institutionalization which could run, I am told, between $40,000 to $50,000 a year, assuming that a nursing home could be found willing to take on an Alzheimer patient. Few middle income families are in a position to withstand such expenditures. Only low-income families are given help under Medicaid. Each person from the day of birth is a possible candidate for partial or total institutionalization. Each of us is subject to this catastrophic consequence. Yet at present there is no adequate insurance available for this contingency.

Statisticians with reasonable certainty should be able to predict the probabilities, at birth and at various ages, for the necessity of institutional care for a person, and to compute the probable cost. The statistical approach is relied on by insurance companies for health and all other types of insurance; and there is no reason why such additional protective insurance should not be made available to defray the costs, wholly or in part, of institutionalization, be it necessary for physical ailments, mental diseases, or other conditions which require such measures, subject to adequate reasonable controls where admissions may be made only upon proper certification by one or more physicians or psychiatrists.

I respectfully urge this committee to confer with members of the insurance industry and other officials with a view towards establishing the availability of such catastrophe insurance at premiums that would be fair to the public and yet profitable to the insurance carrier.

Four. With the present national debt being what it is, there is little hope in the near future for national health insurance, but some day it may be possible, at which time measures should be provided for the care of the sick, infirm, and mentally impaired.

Five. The immediate needs of Alzheimer patients and their families call out for a viable community service as an alternative to institutions. This should be funded by the State and Federal Governments and should provide for full and part-time at-home care for Alzheimer and other mental patients. Part of the costs for the service could be paid for by the patient's family, but such contributing costs should be fair and modest. Such service organizations should be established in each community. I think such community service, if properly functioning, would be the choice of most Alzheimer's families. Treating mental health patients at home is cheaper for the government than warehousing.

Six. Day care centers in each community should be established with skill to handle Alzheimer and other mental patients during the day, where families may bring the patient with assurances of proper care. I have in mind centers such as has been operating at the COPSA Day Hospital in New Brunswick, which I personally visited. The patient is exercised, stimulated mentally and emotionally within the limits of his capacity, fed and entertained, and cared for under established effective daily programs.

I must commend Mildred Potenza and others there for the excellent and effective service they are rendering. Many more such day care centers should be established and become functioning. While these day care centers are of no help to me, they nevertheless afford many families at least some respite during the day from their many responsibilities toward the Alzheimer patient under their care. To the extent such day care centers require funding, the State should help.

Seven. Last, I think that the support groups which meet in some communities are of help to caregivers affording an outlet for venting frustrations and giving up-to-date information on the problems. The support group I attend is under the charge of Maryanne Benson who has been kind and supportive. She is devoted, cooperative, and efficient. I have only words of praise for her. I thank each and every committee member for their interest and service to this cause, and I thank each of them for the opportunity afforded me to relate my Alzheimer problems and express my views.

Thank you.

Mr. RINALDO. Mr. Wollin.

STATEMENT OF LONNIE A. WOLLIN, DIRECTOR, ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOCIATION

Mr. WOLLIN. I would like to thank you, Congressman, as well as Congressmen Saxton and Courter, for inviting me here to speak as well as holding this hearing.

As the Congressman indicated, I founded the New York City chapter in 1977, Alzheimer's Disease and Related Disorders, and along with six other individuals founded National ADRDA. And I am still an officer and director. ADRDA presently has 125 chapters nationwide and 809-plus affiliates and support groups throughout the country. It is truly a grassroots movement. It has been spreading like wildfire. In 1980, our budget was $98,000. This year we expect in excess of $5 million. It has doubled every year since inception. Recently, we formed a New Jersey Chapter of ADRDA, which will be headed by Mrs. Eleanor Ebner.

My history in Alzheimer's is a long one. My father, three of his brothers and two of his sisters have had the disease. Two are still alive. I have a horror story in just about every category that you can think of. I am standing here as an Alzheimer's time bomb, and there are many theories of what causes this disease, one of which is genetic. Clearly, if that is the case, I am a product of that, sitting with a 50-percent chance. I stand here with a sword of Damocles above my head. I am earning, contributing to society, and I pay taxes. If the sword falls, all of that changes. My resources will be drained or will be legally transferred to avoid draining. I will become a ward of someone or something. I will fit into the excellent description that Mr. Phillipson made for caring for his wife.

As has been stated, 2.5 million Americans suffer from the disease and more than 125,000 die each year. It is the fourth leading killer in America today. Thirty-five percent of all nursing home populations are Alzheimer's patients. It is my understanding that more than $30 billion per year is being spent on that care, and it is growing geometrically, and as the baby boom population comes into their fifties, sixties and older, this will be as Louis Thomas said, the disease of the century. The disease has struck people as young as 27, and it has been found in people way into their nineties. The usual age is in the fifties, and sixties. When I reach 50, my son will be 20, and my daughter will be 18. That is the time when they need me for college and everything else. If the sword falls, I will not be there for them. Research presently is $49 million, and that is a joke. The New York Times put out a schedule of research, with dental research being $44 million. We either have to pay now or pay later, I think. I think with research, if we invest, we are investing in the future, and we can invest millions now, and maybe hundreds of millions, we will save literally billions later, in terms of taxes, direct costs of care, productivity of society.

Without this commitment for cure, I have one simple suggestion, which is a personal one, having nothing to do with my affiliation or for any association. If the commitment isn't made to cure this disease, that I be allowed to die with dignity, while my family can retain pleasant memories rather than watching me waste away slowly and painfully. I would rather be put to death with a lethal injection or even starved to death than go through the final stages of the disease. Though it begins with a simple loss of memory or speech, which creates frustration and depression and the victim loses his or her identity, loses the ability to perform a simple task, such as feeding one's self or clothing one's self, and then it progresses much worse. That is the easy part of the disease. There is a slow and agonizing process of death, incontinence, inability to swallow, with walking becoming a shuffle, a glazed look, all the way into a coma. It is long and painful and usually ends with pneumonia, or water in the lungs, causing heart failure. This is not the way to go. As Roswell Gilbert had, and I have to say that I feel for the man, and I hope that somebody will have the courage to do it to me, if I should be unfortunate enough, if we can change the laws in that regard, I would not be unhappy. Our system of government guarantees life, liberty and the pursuit of happiness, but our constitution does not force that right on us. If I were to choose to waive that right, I would like that.

From a family point of view, the family usually experiences denial, confusion, tremendous loneliness, depression, hopelessness, and then they go into the bad parts: emotional upheaval; seeing a loved one in such a state; going through the 36-hour days as a caretaker and caregiver, not being able to sleep because the patient keeps them up all night and the patient sleeps during the day. Seven days per week, 365 days per year, taking anywhere from 4 to 17 years of this hell.

The financial disaster has been mentioned. Either through home care or nursing care, the costs are between $10,000 and $40,000 annually. There is a point beyond which home care is impossible. If somebody, say, were to have a home that cost them $30,000, which is presently worth $200,000, and they have savings of $40,000, how long is that going to last? What happens to the survivor when they are gone? Social Security and pension just aren't enough. My Aunt Shelley is presently living in the final stages of Alzheimer's. Her husband, 72 years old at the time it was diagnosed, had lost a leg in Guadalcanal and was on a disability pension from the Army, as well as a pension from where he worked after the war. They had put together $50,000 in savings. They had to transfer the assets and wait 2 years before they would qualify for Medicaid. I don't know what my uncle is going to do for the rest of his life. When I was in Washington, last year, to meet with President Reagan in the Oval Office, to acknowledge Alzheimer's, we walked by the Veterans' Administration, and I happened to have taken a picture of the plaque on the building. It says, "To care for him who should have borne the battle and for his widow and/or family." I don't think my uncle feels that that is a true statement today.

My Uncle Lou was in a veterans home, here in New Jersey, many years ago. He was told to leave because they didn't have room. They also said that there was at least a 6-month waiting period in a nursing home.

We need more care. Once in the nursing home, there is a tremendous inability of many nursing homes to provide care for these victims. There is a tremendous lack of knowledge at all levels, though it has improved over the years.

What we need, in a nutshell, is research, somewhere in the neighborhood of $350 to $500 million per year, together with a commitment. We have to consider the caregivers like Mr. Phillipson and others throughout the country, in the form of home care, adult day care, to create respites, which should be proliferated throughout the State.

Nursing home care must be improved, must be paid for. We have to declare Alzheimer's a catastrophic illness, which it is, change the Medicaid definition, educate the people, the health care professionals throughout the State, to encourage private and possibly create public insurance to cover the cost of this terrible disease and to help, get some kind of help and understanding from the Veterans' Administration.

Thank you very much.

Mr. RINALDO. Ms. Fell.

STATEMENT OF SUSAN W. FELL, PRESIDENT, ALZHEIMER'S DISEASE FUND OF NEW JERSEY

Ms. FELL. Thank you for the opportunity to testify today on behalf of the Alzheimer's Disease Fund of New Jersey, Inc. [ADFNJ]. My name is Susan W. Fell and I serve as president of ADFNJ. My family and I helped found this organization on March 8, 1984, 1 day after the death of my father, Russell L. Wyckoff, from Alzheimer's disease at age 68.

Fortunately, much information is available today about this disease, but in the 1970's when my father was seeking a name for his memory loss problems, none of us had ever heard of Alzheimer's disease.

In 1948 my parents founded a weekly newspaper in Union County. As publisher, my father was extensively involved with both community activities and the newspaper field. He was energetic, creative, and of course relied heavily on his good memory as he built up the family business.

We are not exactly certain when he first contracted Alzheimer's disease, but his initial memory problems were later coupled with erratic behavior which seemed to have no cause nor explanation. As all those around him grew ever more confused and agitated about his state of mind, his condition rapidly deteriorated, finally rendering him totally incapable. This one-time company president was reduced to a childlike state. The only chore he was capable of performing was trimming the excess paper from the borders of ads.

After Alzheimer's disease was finally diagnosed, several CAT scans and numerous tests later, we tried to lead a fairly normal life, but found that to be impossible. On one occasion, my father insisted that he could drive alone to my parents' winter home in Florida, but he became confused by the road signs and was lost for nearly 3 days. When he finally arrived, he had no idea of where he had been. We were forced to steal his car from him and forbade him to drive thereafter. Sometime later, back in Westfield, he wandered into the downtown business district one afternoon and approached a traffic patrolman on duty, seeking to purchase a gun. Before he could be escorted back to our parents' apartment, he had also visited a book store, a shoe repair shop, a furrier, and a stationery shop, still looking for a gun. Thank God we will never know what he might have done had he been able to obtain one.

Finally, after months of wandering and increasingly strange behavior, the family elected to place him in a local nursing home where, despite the excellent care he received there, his condition deteriorated steadily until his death. At the same time, my maternal grandfather, who will be 86 next month, is also a victim of Alzheimer's disease and is in another area nursing home. For approximately 2 years, my mother had both her husband and her father residing in nursing homes, suffering from Alzheimer's disease. Our family was fortunate to have the resources to pay the nursing homes, but this is not the case with so many other families, whose entire life's savings can be wiped out by this dreadful disease.

It is for these reasons that ADFNJ was founded, to raise funds to help local families deal with Alzheimer's disease; to provide money to help with day care or home care so family members can have some respite from their exhausting caregiver duties; and especially to offer information about the disease and to direct people to other groups such as National Alzheimer's Disease and Related Disorders Association, the newly opened institute in New Brunswick, various local self-help and support groups, county and State agencies, and the like. The ADFNJ office is staffed by a paid part-time project coordinator and several volunteers who help answer the always-ringing phone and perform various administrative duties.

When a caregiver calls the office, we are now equipped to give them the information they so desperately need. Many feel that this cannot be happening to them, and want to just tell our worker about the symptoms they are noticing in their spouse or parent. We suggest they see their family doctor for a thorough examination and send them a brochure we have that answers the most commonly asked questions about the disease.

Our bulletin board has all the latest information distributed by the New Jersey State Department of Health and its gerontology program. We have the complete listing of the Alzheimer's disease support groups in the State. These are listed geographically and give the name of the contact person, the telephone number, and the location, date, and time of any regularly scheduled meetings. This is especially helpful when we get a call from someone in one town who has a relative with Alzheimer's disease living in another part of the State.

Indicative of our efforts at community involvement and professional education, ADFNJ recently sponsored a symposium on the latest advances in Alzheimer's disease research at Overlook Hospital in Summit. Dr. Richard Mayeux, an associate professor of clinical neurology at the College of Physicians and Surgeons, Columbia University, spoke on his ongoing research efforts before an audience of over 100 doctors, nurses, and concerned area residents. A videotape of the entire symposium was made and is available for viewing by interested parties.

One of our major future goals will be to develop a statewide communication plan to coordinate the flow of information. We hope to publish a newsletter on a regular basis that would include timely material from all the groups involved in combating Alzheimer's disease.

Last November our first annual forget-me-not ball raised $20,000. We donated that to the Adult Day Care Center at Memorial General Hospital in Union and to COPSA in New Brunswick.

This year, in conjunction with our annual ball, we are developing a unique concept aimed at increasing corporate support. It is called the Corporate Patient Scholarship Program and is designed to fund adult day care or home care scholarships for a 6- or 12-month period. Presently the advisory board consists of representatives of the following: Allied-Signal, Inc.; the Honorable Chuck Hardwick; COPSA; New Jersey Bell; New Jersey Department of Commerce; New Jersey Department of Health; Shanley & Fisher; Touche Ross & Co.; United Jersey Bank, N.A.; and WJDM Radio.

We hope to raise $50,000 from this year's forget-me-not ball on November 22, 1985, at the Hyatt Regency in New Brunswick.

Thank you for allowing me this opportunity to speak about what I consider to be the most devastating and emotionally costly illness now afflicting older Americans and their families. As our group's slogan says, we must: "Remember, for the sake of those who can't."

Thank you.

Mr. RINALDO. Ms. Epstein.

STATEMENT OF CAROLYN EPSTEIN, MSW ASSISTANT EXECUTIVE DIRECTOR, SAGE, SUMMIT, NJ

Ms. EPSTEIN. Thank you for the opportunity of being here today. I represent a community-based agency providing numerous social services to the elderly, founded over 30 years ago. The programs in our agency have developed and evolved in response to community needs. Just over 10 years ago, our adult social day care program, Spend-A-Day, was started in response to a need on the part of one of our volunteers whose husband was suffering from a dementia of the Alzheimer's type. She was at her wit's end and this program came out of several meetings and support for her individual problem. Only in the more recent years have Alzheimer's and Alzheimer's-type dementias been recognized as a bona fide social problem.

Out of this meeting or in this need arose plans for a support group for caregivers which our agency has operated for several years now. The Adult Day Care Program grew from a 1-day-a-week program to a 5-day-a-week program with expanded hours to accommodate working caregivers' schedules. We are one of four providers of day care in Union County, and although our program is categorized as social day, we currently accommodate a wide range of physical and mental impairments. We have found that our program is able to provide limited help for Alzheimer's victims and their families, if intervention comes early enough.

In the early stages of dementia, the victims are better able to relate to a group setting and the familiarity of the program enhances their ability to function in this setting as the disease state advances. Our social day program doesn't afford the staff ratio to accommodate a complete population of Alzheimer's victims. Again, it depends on their individual levels of impairment. We have accepted several Alzheimer's victims, and they have done well in the program. Those that we have accepted in the more advanced and difficult stages for short periods of time, to provide a respite for the caregiver, we have found we have had a negative impact on the program overall. That is so because in the advanced stages, victims need 1-to-1 supervision, which a group staffing ratio in a day care program such as ours doesn't afford. And these people become disruptive and agitated at the normal programing that is effective for earlier states of dementia. There is a real need for special programs such as COPSA and additional staffing and day care programs where the target population is specifically geared toward Alzheimer's victims.

To address the needs of the families of Alzheimer's victims, we need to look at the many, many stresses that this disease places on caregivers. One of the greatest and probably the most important superficial need is that of respite care. By providing some respite, it prolongs the ability of a caregiver to cope with the daily responsibility and it relieves the stress that is built up and reduces the potential for verbal and physical abuse in crisis situations. If only one service could be provided for families, our opinion is it should be a respite care program. Families have told us that without this type of respite on the home care and day care front, they would suffer such undue hardships, it would force them into considering institutional placement before they were prepared to do so and before it was the last alternative.

Other needs of the families include education so they are able to learn more about what their loved one is going through and what they might be able to expect. They also are in need of support from professionals and also peer support through the self-help groups that have developed throughout the State. There is a need to help them manage the ongoing and continuous stress that they have in their task as a caregiver. There is a great need for financial planning and assistance, and certainly not to be minimized, good medical support and counseling from a medical perspective as well as a social perspective.

I can't stress the importance of early recognition, planning and integration into community-based programs to help families and victims of this disease. The Alzheimer's victims themselves need to be assured of a safe environment and of caring and supporting supervision. They need stimulation, when stimulation is appropriate, and they need, at later states of the disease, need to be free from overstimulation and day-to-day things that would cause them increased confusion.

The victims themselves need education in order to help them understand as best they can at different points of the disease state what they are experiencing. Day care programs enable, as was stated in previous testimony this morning, Alzheimer's victims to retain a sense of self-esteem and self-worth. They also need legal protection, and I believe that I can go on. These are the points that I was able to highlight.

I do believe that national attention and recognition of this problem will enable us to provide a better coordinated system of care, both for the caregivers and the victims of this disease.

It is really an astronomical problem that we in gerontological services are seeing increasingly.

I believe that our society has a responsibility to try to minimize the impact of the disease.

Thank you.

[The prepared statement of Ms. Epstein follows:]

PREPARED STATEMENT OF CAROLYN EPSTEIN, MSW, ASSISTANT EXECUTIVE DIRECTOR, SUMMIT-AREA ASSOCIATION FOR GERONTOLOGICAL ENDEAVOR (S.A.G.E.) SUMMIT, NJ

S.A.G.E. (Summit-Area Association for Gerontological Endeavor) has been providing services to the elderly for over 30 years. Just over 10 years ago our Spend-a-Day

Adult Social Day Care Program was started in response to a need on the part of one of our volunteers whose husband was suffering from a dementia of the Alzheimer's type. The program has grown from 1 day to 5 days a week with expanded hours. The program is categorized as social day care but currently accommodates a wide range of physical and mental impairments.

We have found that our program can provide limited help for Alzheimer's victims and their families if intervention comes early enough. In the early stages of dementia, the victims are better able to relate to a group setting and the familiarity of the program enhances their ability to function in this setting as the disease state advances. Our social day care program does not afford the staff ratio to accommodate more than a limited number of Alzheimer's victims in the early stages. We have accepted more advanced and difficult cases for short periods when the family has been in crisis. This has often been a negative influence on the other program participants and is not something that we are able to do on a regular basis. Many Alzheimer's victims need one to one supervision and are disruptive in a group setting.

To address the needs of the families of Alzheimer's victims we need to look at the many stresses this disease places on caregivers. One of the greatest and probably the most important need is that of respite care. Respite care prolongs the ability of caregivers to cope with the daily responsibilities of care for longer periods. Providing respite also relieves stress build up and reduces potential for verbal and physical abuse. If only one service could be provided for families it should be respite care. Families have told us that without respite they would suffer hardships that would push them toward institutional placement.

Other needs of families include but are not limited to: education about Alzheimer's, support from professionals and peers, stress management, financial assistance, good medical supports, counseling from community based agencies. Again, I cannot stress the importance of early recognition, planning, and integration for families and victims of this disease.

The needs that we see day-to-day for Alzheimer's victims are: safe environments, caring and supportive supervision, limited stimulation and confusion, education, and legal protection.

Mr. RINALDO. Mr. Pearlman.

STATEMENT OF PHILIP H. PEARLMAN, DIRECTOR, UNION COUNTY DIVISION ON AGING, ELIZABETH, NJ

Mr. PEARLMAN. Congressman Rinaldo, other distinguished Members of Congress, honored guests, fellow senior citizens, ladies and gentlemen. I am pleased you have chosen Union County as a site to gather more information on Alzheimer's disease and I am both honored and pleased to offer testimony to you. As director of the Union County Division on Aging, I represent a staff and a social service network which shares the national concern for this horrendous disease. If I may, I would like to share with you information within three areas regarding Alzheimer's disease as it relates to the Union County Division on Aging. What we are doing, what are the unmet needs, and what we view as our future role.

The Union County Division on Aging developed and implemented a coordinated community care program for elderly residents of the county in 1981. Through that countywide program, we provide homemakers, home health aides, nurse supervisory visits, and adult day care. The elderly residents of the county receiving these services suffer from a number of ailments, Alzheimer's being one of them. These home care programs are funded by a combination of three funding streams, OAA, title II, title XX, and funds from the Union County Board of Social Services. All of these funding streams are finite, as you know, and, therefore, can provide only a limited amount of service. Alzheimer's patients need increasingly greater amounts of service as the disease progresses. The primary caregivers of these patients also need increasing amounts of service to give them respite from their 24-hour, 7-day-a-week responsibilities.

In addition to these services, many of the other programs funded through the division provide service to Alzheimer's patients and their caregivers. Home-delivered meals, paratransit and legal services are typical of these services.

The services and programs referred to above and noted as being finite are basic and important in attempting to maintain the Alzheimer patient in his or her home and providing the primary caregiver some respite from their endless job. The ability to provide services in relation to the need is hampered by the age-old problem of money. Many Alzheimer patients and their families cannot afford the full cost of home care. The reluctance of Medicare to address home care as a less expensive and more humane mode of care versus acute care in hospitals puts a severe strain on our limited title III and title XX funds. I would encourage Congress to consider expanding Medicare coverage of home care particularly for Alzheimer's patients.

There are other areas of unmet needs which should be addressed. The general population needs education and information so they can understand and appreciate the tremendous difficulties imposed on Alzheimer patients, their caregivers, and families. Although we do not have clear demographic data on the incidence of Alzheimer's disease, we know many of the residents of the county receiving home care and adult day care services through our coordinated system are Alzheimer's patients.

The inability to provide more home care and adult day care is a major unmet need. These modes of care not only serve the patient, but the primary caregiver who is usually a family member who needs respite from their never ending chores and duties. Increased research to find the cause and ultimately the cure for Alzheimer's disease is also a high priority. Increased training for professional and nonprofessional caregivers to better equip them to serve Alzheimer's patients is a need. More training for police and emergency personnel, who often come in contact with Alzheimer patients, is a need. We need more trained facilitators for self-help groups who can sustain and assist primary caregivers. The sensitivity and awareness of health insurance carriers should also be addressed so the strain on Medicare, title III, and title XX can be reduced. I am sure there are other areas which can be expanded and improved. Even within the areas I have briefly mentioned are many subparts which can be expanded upon. Underlying all the unmet needs is the need for stronger focus on Alzheimer's disease by all segments of our society: government, private companies, individuals, researchers, and service providers. It is a monumental task and needs support from everyone.

We will maintain our position as the focal point of planning and coordinating services for the elderly residents of Union County. That position will include a focus on the needs of Alzheimer's patients, their caregivers, and their families. Through our information and referral unit we will continue to provide for specific information requests and general information through direct phone referrals, meetings of groups, and press releases. This will help in filling the unmet need of public education as well as assistance to the Alzheimer patient and their caregiver. We also intend to be a part of the process that will train caregivers and bring up-to-date information on Alzheimer's to this overworked and generally unrecognized group of people. This training and information sharing will also include the professional staffs of home care agencies and adult day care providers as well as other social service agencies serving Alzheimer's patients and their families.

Another area in which we will have a role is the gathering of data on Alzheimer's patients and their families. This data will help the researchers as well as us as we refine our plans and services for the victims of Alzheimer's disease patients and their families. As part of that effort, I cannot pass up the opportunity offered by this hearing of advocating for increased congressional support in meeting the current unmet needs and perhaps more importantly the anticipated future needs of Alzheimer's disease patients and their families. During these difficult times of Federal budget cuts, the pressures on Congress will give you many difficult decisions to make. I trust the information you already have, coupled with what you will hear today, will keep the needs of Alzheimer's patients and their families in the forefront of your deliberations and decisions.

Thank you again for your attention and the opportunity to appear before you today.

Mr. RINALDO. I would like to direct a question, if I may, to Mrs. Fell. I have a tremendous amount of respect for your father, who was a very distinguished publisher in this county. Mrs. Fell, what do you think, based on your experience, should be the top priority of this committee and the Congress for coming to grips with Alzheimer's?

Is that more research funds? Is that funds to grant to States for programs such as COPSA, or for increasing Medicare reimbursement for Alzheimer's or reimbursement in the first degree?

Mrs. FELL. I believe that the first priority would be to help fund programs such as COPSA, since that addresses an immediate need. I would say that, secondly, the research and Medicare problems which would be in a tie for second. All of the needs are right now, and it is still such a frightening situation, because really you don't know anything about it. We are all a little bit closer, but from the research angle, we know that the patients who currently have been diagnosed as having Alzhiemer's, that it is totally irreversible. Nothing can be done for them, even were they to come up with a drug or whatever that would perhaps stop further deterioration. I think that is what is so frightening about it as well.

Mr. RINALDO. There are many, just to follow up, national organizations that have been founded for a host of diseases, heart association, cancer, disease of the lungs, muscular dystrophy, and others. Do you feel we need such a group for Alzheimer's or is that a role that you and others, such as ADRDA hope to play?

Mrs. FELL. Yes. I think that National ADRDA has done a super job. I think there are so many factors that we need more time like the smaller groups to develop programs, often only in small portions of the State.

Mr. RINALDO. Mr. Wollin, as you probably know, there is strong support in Congress for increasing funding for Alzheimer's programs. Can you give this committee your priorities for strengthening the fight? Can you rank a priority list, first, second?

Mr. WOLLIN. Priority is very tough. I think as Susan stated, you have to spread out your dollars.

There is an immediate need. There are people calling our office who are frightened. They need respite and care. On the other hand, if you don't fund substantial research, you will have this problem for a long time. The only analogy would be polio. Had the money gone into treatment, we would have a magnificent portable iron lung, but no cure for the disease.

I think the dollars that are available have to be spread out between the immediate respite care and research.

Mr. RINALDO. Thank you.

I would ask Mr. Phillipson the next question. Based on the very tragic personal experience that you discussed in your testimony, sir, do you think we are doing a good enough job at the Federal level in educating the public about Alzheimer's?

Do you think we are making the public more aware of the disease? Do you think we are advising people properly about the avenues open to them with regard to this disease?

Mr. PHILLIPSON. I think anybody who has an Alzheimer's patient in his custody or care is able to obtain full information from all Federal sources and state sources now, so that from an educational standpoint, I don't think that is a problem at all.

I think the big problem for the individual who is charged with taking care of an Alzheimer's patient is to find the resources to enable him or her to do so. I think that is where the problem lies. In that respect, if Medicare, and I personally feel, if Medicare could be amended so as to provide for the care of mental patients and to take care of catastrophic illnesses, I think that would go a long way toward helping.

Mr. RINALDO. Thank you.

Mr. Pearlman, in your countywide Coordinated Community Care Program, how many elderly residents are you able to help?

Mr. PEARLMAN. At the present time, through the various funding schemes we have, between 5 and 600 individuals, through in-home care and adult care.

Mr. RINALDO. Of that figure, how many are AD victims?

Mr. PEARLMAN. I don't really know. We never really tried to ascertain that. Only recently have we become aware of the fact that many of the patients that we serve are Alzheimer victims. As my testimony indicated to you, one of the things that we plan to do in the future is to try to identify the individuals, so that we can start to develop a data base for the research and our own planning needs.

Mr. RINALDO. Any idea how many Alzheimer's victims there are in Union County that you can't serve because of a lack of funds?

Mr. PEARLMAN. Sorry, I don't.

Mr. RINALDO. Thank you.

Ms. Epstein, I would ask you a question, if I may. Based on your own personal knowledge, do you feel that the medical profession is up to date in recognizing Alzheimer's? In previous hearings, there was testimony that it was only recently that the medical profession became aware and was able to recognize this. Do you think that the profession is assisting families as much as possible in coping with the effects of the disease?

Ms. EPSTEIN. As to the first question, with regard to the medical, I would have to answer no. We have found, unfortunately, many GP's, many doctors who are not as up to date on Alzheimer's, and its effects, as they could or should be, and it is difficult to know where to send families who want a physician who specializes in geriatric care.

There are some increasing numbers, and it has been very encouraging that our local hospital is now putting more of a priority on a geriatric component in training their family practice physicians. This has been a sadly lacking area. Second, in terms of professionally assisting families, if you could clarify the question to me?

Mr. RINALDO. Do you feel that people who come to you, or if somebody came to you, asking it this way, from a rather basic point of view, if somebody came to you and felt that a member of their family had Alzheimer's, what advice would you give to that person? Where would you send them? Do you think that in this area you are able to accurately diagnose and that there is effective care for that person?

Ms. EPSTEIN. There would be a number of things that I could do, if a person came to me with that problem.

I think that we do have good resources in our area. However, a concrete diagnosis, well, that is difficult. They would need to get a diagnosis of Alzheimer's-related dementia, a true diagnosis only being available on autopsy.

But I could refer them to a medical person for a diagnosis and then I would be able to help them establish a plan of care and funnel them, or stream them into our support group, work with them to handle the day-to-day problems, and the most pressing problems, which are the concrete social services, at that community based level.

I think we have made inroads into that, with our home care programs, with our adult day-to-day care program, and with the other programs that Mr. Pearlman mentioned. I would not at this point say that if somebody came to me, that I would throw up my hands and say this is a terrible thing and I can do nothing. That isn't the case. I feel that we do have a long way to go however, to provide all the services needed.

Mr. RINALDO. Putting into effect all of the programs that you mentioned, what would be the estimate for home care, on an annual level, that a family would have to sustain?

Ms. EPSTEIN. Looking at care for the elderly, most families wish to do their very best for the person they care for. They are not looking to dump them into a nursing home. They are not looking for 24-hour-a-day home care. They are more than willing to carry their share of the burden. What they want to do is maintain their sanity and health in doing so.

Home care or adult day care, when used in combination with other support services, would probably be somewhere less than 50 percent of what institutional care would cost. It could be as little as 25 percent of what institutional care would cost, to provide an array of services that would assist families in being able to serve as the primary caregivers and to do so in an effective manner in the community.

Mr. **Rinaldo**. In dollars, what would the total annual cost be?

Ms. **Epstein**. Nursing home costs of about $40,000 per year, so we are probably talking somewhat less than $20,000 per year.

Even $5,000 to $10,000 in home care and day-care moneys go a very long way.

Mr. **Rinaldo**. Thank you very much.

Mr. **Courter**. Mr. Pearlman, your program in the county, where does your source, your sources come from? State, local, Federal private?

Mr. **Pearlman**. Primarily Federal moneys. We are the Area Agency on Aging in Union County. We get title III funds. We also have social service block grant funds, and funding from the county board of social services. Those are our primary funds. Currently, we have a demonstration program in the county, and we are one of five counties in New Jersey who have the home health demonstration grant. This past month we became one of the counties involved in the State's Medicaid waiver program. So, these in combination are primary sources to provide care.

Mr. **Courter**. Do you work pretty closely with the State?

Mr. **Pearlman**. Yes.

Mr. **Courter**. Mrs. Fell, what generally, if an individual who does not know a great deal about Alzheimer's disease comes to you, or comes to an organization, and that individual is asked for preliminary information, what information is provided to them? Is that oral, is that counseling the first day as to what may or may not happen?

Mrs. **Fell**. Mostly telephone and written information. People call up trying to determine what doctor they might be able to go to, whether there are specialists in the field. They are looking for area support groups, and we would refer a lot of people to Brunswick COPSA. We keep updated computerized lists of support groups.

Mostly, though, they call to talk. They have a great deal of difficulty in believing this is really happening to them and to their family. I would say most of our volunteers spend a lot of time on the telephone, on a consistent basis just listening.

Mr. **Courter**. How many different institutions are there in the State of New Jersey, if you know, that will handle victims of Alzheimer's disease?

Mrs. **Fell**. We really don't, but there are more and more every day. Hospitals are starting programs that didn't have them before. We can tell just from our clipping service that a number of different programs are starting.

The work that the State is doing in setting up the institute and the resources; everybody can find out more and more what hospitals are doing, and churches have set up support groups. A lot of people are involved, but I don't have specific numbers.

Mr. **Courter**. Mr. Phillipson, if I can ask you a question, you indicated that at one time in your testimony there was a doctor who indicated about a shunt operation, I believe.

Mr. **Phillipson**. Yes.

Mr. **Courter**. Can you elaborate on that? I know you are not a doctor, but what did the doctor say about it?

Mr. PHILLIPSON. He was going to drill a hole into the back of the skull and put some sort of tube which ran from the brain section into the stomach. That tube would remain in the system. It is called, medically, the shunt. The idea is to relieve a certain section of the brain from some of the liquid or pressure that builds up there. He thought that would be a good idea.

Mr. COURTER. This is for anybody on the panel, and I gather from the sense of the testimony today that we should do what we can to have victims of Alzheimer's disease at home, provided there be somebody in the family who can care for them, until a certain stage of the illness or where the family member doesn't have the energy to provide the care at a later stage.

Does anybody disagree with that, that that is going in a wrong direction? Does anybody think we should increase the possibility of institutionalization for victims of the disease? Or does everybody on the panel come down on the side of the home care, provided there are family members who can render such care?

Mr. PHILLIPSON. Seems that home care is by far the best.

Mr. COURTER. Why?

Mr. PHILLIPSON. To begin with, they require 1-to-1 care. In the hospital or in an institution, they cannot possibly get that type of care, that level of care. The homemaker, though, needs help. With some help, though, he or she can carry on. I am speaking of myself.

Mr. COURTER. Anyone on the panel, speaking of day care. You go through an awfully long and arduous and emotionally difficult day.

Are there times you can't go on any further?

Mr. PHILLIPSON. I would love to be able to take my wife to a place and leave her 2 or 3 days a week for a few hours per day. Her condition is so advanced that I can't take her out any more.

Day care is wonderful for situations where patients can be taken to centers. COPSA is an example of one. They do wonderful work there. They take care of the patients for 2 or 3 hours a day. That is a tremendous relief for the caretaker of the Alzheimer patient.

Mr. COURTER. Can you go out to buy groceries and household supplies in your household, sir, in light of the fact that your wife needs constant care?

Mr. PHILLIPSON. When I say constant care, I have to pay attention to her situation at all times. I can leave her. I can. She is being left at this present moment. She is in her chair, talking to herself. She is absolutely safe.

Mr. COURTER. Alone now?

Mr. PHILLIPSON. She is at home at this moment. I must get back to prepare her lunch and so forth. As far as shopping is concerned, I do all of that.

Mr. COURTER. Thank you. Thank you everybody on the panel.

Mr. SAXTON. If I can change direction just a bit, I have a booklet that was published by the U.S. Government, an accumulation of information as to various aspects of the Alzheimer's disease and condition. One of the conclusions that one must draw from the booklet is that when it comes to the research that we have done, it seems to me at least, that we have begun only to scratch the surface.

I was wondering if any of you could comment on research that has been done regarding possible causes, which indicate that perhaps part of the problem comes from a possible genetic defect.

There is a typical infectious agent or something known as a slow virus which may have something to do with it. Other causes may be: accumulation of aluminum in the brain, possibly from environmental sources; and a calcium reduction by certain cells that do not perform correctly.

It doesn't go far to point out that we do not know in any great depth or detail as to what the causes might be. It follows that we do not know anything more than that about the cure, if we cannot determine causes. What type of research is being done? What type of progress have we made, if any, other than identifying these possible causes? What do you see in terms of the future, given a proper level of funding of research by the Government?

Mr. WOLLIN. As you have indicated, there are a number of theories, with nothing determined specifically. There is genetic, slow virus, an aluminum theory, because in the autopsy of brains of AD victims, there is an inordinate amount of aluminum in the brain. They don't know if that is cause or effect. That is clearly a substantial increase over norm. There are theories with regard to the immunity system. I think one thing we have to understand is that, about 90 to 95 percent of what we know about the brain has been learned in the last 15 to 20 years due to the electron microscope, CAT-scanners, and the like.

In terms of the research going on, they are in every single field mentioned, to determine the genetic component or marker. To do epidemiological studies to see what effect the environment has. There have been studies on twins. I am happy to report that in identical twins, where one twin got it, in only 50 percent of those studied, did the other get it. In a case studied, there was a 14-year difference in the age of onset.

You have two people with identical genes developing a disease 14 years apart. If we can determine what in the environment prolonged onset, we have 90 percent of the battle done. In terms of what research to fund, the National Institute of Health is extremely qualified to and has the scientific boards specifically designated in Alzheimer's. Many of the members are on the medical and scientific advisory board of ADRDA and issue grants for our research program. The key would be to approach the NIA to ask them where the best would be, but for the most part, it would be spread out among the various things that you mentioned.

Mr. SAXTON. You mentioned NIA?

Mr. WOLLIN. Yes. Age is also involved in this. I try to get away from the mental health aspect of it, because that has created a problem in the past, in terms of nursing homes. They would not take "mental patients." Alzheimer's is a disease that is a physiological disease. There are physiological changes in the brain and brain cells, distinguishing it from mental or emotional illness.

Yes, NIA or National Institute of Mental Health has been active in research.

Mr. SAXTON. You said the Federal Government currently proposes $56 million a year?

Mr. WOLLIN. I thought it was $49 million, but I stand corrected.

Mr. SAXTON. How is that aid distributed or used? Does the government have a program for it which does research, at NIH?

I know Johns Hopkins is involved.

Mr. WOLLIN. Part was a result of ADRDA request for centers of excellence. I believe three and a half million each went to three or five centers.

Originally five, and it may have been cut back. I am not sure whether it has been restored. Mount Sinai in New York, and Johns Hopkins being another. There are two or three others that have received these funds over a period, I believe, of 2 to 3 years, to become centers of excellence for research as well as day care. Whether it is going through NIH or NIMH, I really don't know. But they do have the expertise, and they have called scientists from throughout the country to decide upon various requests for grants that have come throughout the country.

Mr. RINALDO. I would like to thank the panel. We have been having here and in Washington, field hearings such as these to provide us with some of the local problems that arise.

I think you should be aware of the fact that funding for Alzheimer's has increased dramatically. In fiscal 1984, it was $36 million; in fiscal 1985, appropriation provides $56 million for Alzheimer's, together with an additional $5 million to establish five more research programs.

We appreciate your priorities, because certainly all of you are on the firing line.

Mr. RINALDO. Dr. Davis.

STATEMENT OF KENNETH L. DAVIS, M.D., PROFESSOR OF PSYCHIATRY AND PHARMACOLOGY, MOUNT SINAI SCHOOL OF MEDICINE; AND CHIEF, PSYCHIATRY SERVICE, VETERANS' ADMINISTRATION MEDICAL CENTER, BRONX, NY

Dr. DAVIS. Mr. Chairman and members of the committee, thank you for the opportunity to speak before you here today. I am Kenneth Davis, a professor of psychiatry and pharmacology at Mount Sinai School of Medicine and chief of psychiatry at the Bronx VA Medical Center. I would like to talk to you about the research we have been conducting toward developing a drug treatment for Alzheimer's disease, a health problem that is well known to this committee.

Alzheimer's disease is now recognized as the most common cause of serious loss of cognitive function in the elderly. The principal symptoms and neuropathologic hallmarks of AD have been known for some time; clinically, these patients are characterized by progressively worsening memory, gradual loss of language ability, and praxis function, and, occasionally, agitation, violence, or other grossly disturbed behaviors. The principal neuropathologic features are neurofibrillary tangles and senile plaques; because the neuropathologic features are the same regardless of whether onset comes before age 65—presenile—or after age 65, the term Alzheimer's disease or senile dementia of the Alzheimer's type [AD/SDAT] is used to refer to all such patients. Epidemiologic studies indicate that from 5 percent to 10 percent of all people older than age 65 suffer various dementias. Of these, approximately 50 percent have Alzheimer's disease [AD], 20 percent have multi-infarct dementia [MID], 20 percent to 25 percent have neuropathologic features of both AD and MID, and the remaining 5 to 10 percent have rare forms of dementia.

In the United States, approximately 1 to 1.5 million people older than 65, out of 25 million, probably have AD. Since nearly all victims of AD eventually require complete custodial care, these figures demonstrate both the enormous suffering and personal loss caused by this disease as well as the effect it will have on the cost of health care in our nation.

Currently there is no treatment for AD but, recent research on the neurochemistry and psychopharmacology of this disease has raised the possibility that an effective treatment may ultimately be developed.

A series of studies conducted in the United Kingdom in 1976 and 1977 reached an extraordinary conclusion about Alzheimer's disease. Three laboratories working independently reported that in AD, there was a loss of brain cells that made the neurotransmitter acetylcholine. This conclusion was based upon the discovery that the enzyme which synthesizes acetylcholine, and is only found in brain cells that make acetylcholine; that is cholinergic neurons, was very much reduced in the brains of patients with AD.

This finding led a number of research groups, including our own at Mount Sinai School of Medicine and the Bronx VA, to suggest that a possible treatment for AD would be a drug that could increase brain cholinergic activity. Such an attempt was particularly appropriate to our research ward, because we had been investigating a drug that increases brain acetylcholine, physostigmine. Physostigmine inhibits the breakdown of acetylcholine. In fact, while neurochemists in the United Kingdom were finding that the brains of patients with AD had a cholinergic deficit, our laboratory was conducting a study of the effects of physostigmine on memory in young normal people. We found that the administration of physostigmine to young normal people could improve their ability to remember new information and this simultaneous discovery of the acetylcholine deficiency in patients with AD, and the ability of drugs that increased brain acetylcholine to enhance memory, led to the idea that the memory disorder in AD might be improved with drugs like physostigmine.

Together, the neurochemical and psychopharmacologic data provided a strong rationale for clinical trials of cholinomimetic drugs in patients with AD. Unfortunately, a limited number of drugs are potential candidates for cholinomimetic therapy. Physostigmine and arecoline, the most readily available cholinesterase inhibitors and cholinergic agonists, respectively, both have the disadvantage of being relatively short acting with half-lives of about 30 minutes. Long acting cholinesterase inhibitors and agonists such as di-isopropryl fluorophosphate and oxotremorine, respectively are fairly toxic drugs and thus are not good candidates for clinical trials.

The earliest trials of cholinomimetic therapy for AD usually involved either choline or phosphatidylcholine—lecithin—precursors to acetylcholine that are safe even in large quantities and which are normally obtained in the diet. It has been demonstrated in rats that increases in dietary choline or phosphatidycholine are followed by increases in the concentration of brain acetylcholine. Clinical trials, however, failed to demonstrate any acute effect of these precursors on memory or other aspects of cognition, either in unaffected people or in patients with AD. The reason for this failure appears to be that precursors do not substantially affect the rate of cholinergic transmission even though they may increase acetylcholine concentrations.

With the help of a program project grant from the National Institute of Aging, as well as support from the Veterans' Administration, my collegue Richard Mohs and I began a study of physostigmine in AD. We first administered an intravenous form of the drug and then an oral preparation. The initial studies with intravenous physostigmine were encouraging, although the ability of physostigmine to improve memory was hardly as robust as one might have hoped. Still, additional studies were necessary, because intravenous physostigmine is so short acting that it was impossible to adequately assess whether the drug would help patients in daily life.

Studies with oral physostigmine have begun. The drug is given every 2 hours from 7 a.m. to 9 p.m. in doses of 0.0, 0.5, 1.0, 1.5, 2.0 mg. each for 3 to 5 days. On the last day, the patient's overall symptoms are rated with the Alzheimer's disease assessment scale [ADAS] at each dose. This instrument, developed in our laboratory, measures all the principal symptoms associated with AD including memory loss, dysphasia, dyspraxia, aqitation, and mood disturbance. The dose of oral physostigmine associated with the least severe symptoms is then randomly readministered along with placebo for 3 to 5 days under double-blind conditions.

Of the first 11 patients who completed this study, 10 showed some decrease in symptoms with at least one of the physostigmine doses. Of those, eight showed less severe symptoms while receiving physostigmine in the replication phase of the study than they did while receiving placebo. From a clinical perspective, only three of the patients demonstrated enough improvement to be clinically relevant. On the ADAS these patients showed at least a 10-percent improvement over placebo. However, there is a very good reason to believe that not all patients with AD will respond to this drug, nor will all patients who respond to physostigmine respond in the same way. This problem arises from the fact that for physostigmine, which prevents the breakdown of existing acetylcholine, to work, the brain must be able to synthesize some acetylcholine.

Unfortunately, as the disease progresses, cells which synthesize acetylcholine are dying. Because of this problem, we needed some way, besides memory testing, to be sure the physostigmine was getting into the patients' brains. In collaboration with an endocrinologist in our laboratory, Dr. Bonnie Davis, we have found that when physostigmine enters the brain, and acetylcholine containing cells are available to synthesize adequate quantities of acetylcholine, the physostigmine increases the amount of cortisol the patient's body secretes at night. The effect of physostigmine to increase nocturnal cortisol concentrations correlates with the drug's ability to improve the symptoms of AD, as the figure below indicates. These results support the notion that physostigmine only improves the cognitive functioning in those patients whose acetylcholine containing neurons have not yet been devastated by the disease.

Although these results are encouraging to the scientist, for the patient with AD the effects are not as impressive or uniform as one would desire. Instead, they only point to other directions that must be pursued and better drugs that must be developed. Nonetheless, these results with oral physostigmine, which have been replicated in at least five other laboratories, indicate that current approaches are rational.

Given these effects of physostigmine, as well as results from other researchers, there is now need to identify those Alzheimer's patients who may be made modestly less demented by therapies that increase brain acetylcholine. A cooperative study has been proposed by Richard Mohs and myself as well as medical scientists from a number of other VA's, to determine the ultimate clinical utility of physostigmine. We are hopeful that it will be funded, and over the next 5 years, may be able to ascertain just what segment of the Alzheimer's population may be benefited by physostigmine. Such a study can only be done through the cooperative studies program at the Veterans' Administration. It will require extensive coordination of the large study population that is made available by the health care delivery system in the Veterans' Administration. The cooperative studies program has produced invaluable studies of the effects of treatment of high blood pressure, and prostate cancer, yielding information which has saved lives, prevented disability, and saved health care dollars.

Whatever the results of the studies in progress, it is clear that not all patients are going to be helped by physostigmine treatment, and that those patients who are helped will not be returned to normal life. For that reason, additional work is necessary. To that end, our program has been engaged in developing an "animal model" of Alzheimer's disease that may expedite development of other drugs. These studies are made possible by a merit review grant from the VA to me and my colleague, Dr. V. Haroutunian, as well as collaboration with the Hoechst Roussel Pharmaceutical Corp. Together we have found that destruction of a tiny part of the rat's brain can produce a deficit in acetylcholine that in many ways resembles the deficit that exists in AD. This rat model makes possible the screening of drugs for their ability to improve the memory of "demented" animals. We are particularly encouraged by one compound that increases both ACh and NE, another neurotransmitter deficient in some, but not all AD patients. This, and other promising compounds are now being tested in toxicological studies preparatory to human investigations.

The figure below illustrates how physostigmine, the drug we are administering to humans, can reverse the abnormal behavior that animals with cholinergic deficit exhibit. Other drugs such as oxotremorine and 4-aminopyridine, are equally effective at normalizing these animals.

In the future, and with the help of the NIA's ADRC, new drugs that might be more efficacious will be tested, and more importantly, the model will be extended so that it even more closely resembles the human condition. Other neurotransmitter and neuromodulator deficits, particularly of noradrenergic neurons and somatostatin concentrations will be induced. In addition, with the help of funding from VA and NIA, we are now transplanting brain tissue to these lesioned animals in the hope of normalizing their behavior. This will be a difficult process, but one with obvious implications for developing a treatment for Alzheimer's disease.

A major thrust of research in Alzheimer's disease is the delineation of factors associated with an increased risk for the condition. To date, the single parameter repeatedly associated with an enhanced risk of Alzheimer's disease is a family history of Alzheimer's disease. Recent work conducted at Johns Hopkins has particularly supported this claim. Among first degree relatives—mother, father, sisters and brothers—of Alzheimer's disease patients, the incidence of Alzheimer's disease approached 50 percent in those relatives surviving to age 90.

The peak incidence of Alzheimer's disease occurs between the 9th and 10th decades of life. Thus, the majority of Americans do not, yet, live through the entire age of risk for the disease. Consequently, determining the heritability of Alzheimer's disease is made extremely difficult by the fact that most relatives of Alzheimer's disease patients do not live long enough to definitely express, or not express, the disease. Advances in epidemiological and population genetics have made possible the use of mathematical techniques to correct for this problem, and facilitate a more accurate determination of the "genetics" of Alzheimer's disease. Results from our study, in which 244 first degree relatives from 50 Alzheimer's patients were studied, appears in the figure below. Like the Hopkins study, our work also indicates that genetics play a very strong role in the expression of this disease.

The possibility that genetic factors strongly influence the expression of Alzheimer's disease poses a new and exciting challenge to the Alzheimer's disease research centers. The extraordinary advances that have taken place in the last decade in molecular biology, including the cloning of genes, transfer of genes and isolation of gene products, can now be applied to Alzheimer's disease research. At this point, it is impossible to even guess at the discoveries that will derive from merging the powerful techniques of molecular biology with neurobiological methods presently being employed to elucidate Alzheimer's disease. However, the full marriage of these methods, which should occur in the ADRC's, will require additional and perhaps unique modes of funding.

Too often, traditional neurobiologists doing Alzheimer's disease research can conceptualize the molecular approaches that are needed in Alzheimer's disease research, but are not adequately familiar with the methodologies to present a credible proposal. On the other hand, molecular biologists are not adequately familiar with clinical and basic neurobiological issues to conceive of the use of their techniques in diseases like Alzheimer's. Thus, I would propose providing incremental funding, perhaps 20 percent, to each of the Alzheimer's disease centers simply for the purpose of recruiting to the centers molecular biologists with a commitment to apply their techniques to research in Alzheimer's disease.

This concludes my statement, I would be pleased to answer any questions you or members of the committee may have.

[The prepared statement of Dr. Davis follows:]

Prepared Statement of Kenneth L. Davis, M.D., Professor of Psychiatry and Pharmacology, Mount Sinai School of Medicine; and Chief, Psychiatry Service, Veterans' Administration Medical Center, Bronx, NY

Mr. Chairman and members of the committee, thank you for the opportunity to speak before you here today. I am Kenneth Davis, a Professor of Psychiatry and Pharmacology at the Mount Sinai School of Medicine and Chief of Psychiatry at the Bronx VA Medical Center. I would like to talk to you about the research we have been conducting toward developing a drug treatment for Alzheimer's disease, a health problem that has become well known to this committee.

Alzheimer's disease is now recognized as the most common cause of serious loss of cognitive function in the elderly. The principal symptoms and neuropathologic hallmarks of AD have been known for some time; clinically, these patients are characterized by progressively worsening memory, gradual loss of language ability, and praxis functions, and, occasionally, agitation, violence, or other grossly disturbed behavior. The principal neuropathologic features are the neurofibrillary tangles and senile plaques; because the neuropathologic features are the same regardless of whether onset comes before age 65 (presenile) or after age 65, the term Alzheimer's disease or senile dementia of the Alzheimer's type (AD/SDAT) is used to refer to all such patients. Epidemiologic studies indicate that from 5 to 10 percent of all people older than age 65 suffer various dementias. Of these, approximately 50 percent have Alzheimer's disease (AD), 20 percent have multi-infarct dementia (MID), 20 to 25 percent have neuropathologic features of both AD and MID, and the remaining 5 to 10 percent have rare forms of dementia.

In the United States, approximately 1 to 1.5 million people older than 65—out of 25 million—probably have AD. Since nearly all victims of AD eventually require complete custodial care, these figures demonstrate both the enormous suffering and personal loss caused by this disease as well as the effect it will have on the cost of health care in our nation.

Currently there is no treatment for AD but, recent research on the neurochemistry and psychopharmacology of this disease has raised the possibility that an effective treatment may ultimately be developed.

A series of studies conducted in the United Kingdom in 1976 and 1977 reached an extraordinary conclusion about Alzheimer's disease. Three laboratories working independently reported that in AD, there was a loss of brain cells that made the neurotransmitter acetylcholine. This conclusion was based upon the discovery that the enzyme which synthesizes acetylcholine, and is only found in brain cells that make acetylcholine, (i.e., cholinergic neurons) was very much reduced in the brains of patients with AD.

This finding led a number of research groups, including our own at the Mt. Sinai School of Medicine and the Bronx VA, to suggest that a possible treatment for AD would be a drug that could increase brain cholinergic activity. Such an attempt was particularly appropriate to our research ward, because we had been investigating a drug that increases brain acetylcholine, physostigmine. Physostigmine inhibits the breakdown of acetylcholine. In fact, while neurochemists in the United Kingdom were finding that the brains of patients with AD had a cholinergic deficit, our laboratory was conducting a study of the effects of physostigmine on memory in young normal people. We found that the administration of physostigmine to young normal people could improve their ability to remember new information. The simultaneous discovery of the acetylcholine deficiency in patients with AD, and the ability of drugs that increased brain acetylcholine to enhance memory, led to the idea that the memory disorder in AD might be improved with drugs like physostigmine.

Together, the neurochemical and psychopharmacologic data provided a strong rationale for clinical trials of cholinomimetic drugs in patients with AD. Unfortunately, a limited number of drugs are potential candidates for cholinomimetic therapy. Physostigmine and arecoline, the most readily available cholinesterase inhibitors and cholinergic agonists, respectively, both have the disadvantage of being relatively short acting with half-lives of about 30 minutes. Long acting cholinesterase inhibitors and agonists such as di-isopropyl fluorophosphate and oxotremorine, respectively, are fairly toxic drugs and thus are not good candidates for clinical trials.

The earliest trials of cholinomimetic therapy for AD usually involved either choline or phosphatidylcholine (lecithin), precursors to acetylcholine that are safe even in large quantities and which are normally obtained in the diet. It has been demonstrated in rats that increases in dietary choline or phosphatidylcholine are followed by increases in the concentration of brain acetylcholine. Clinical trials, however, failed to demonstrate any acute effect of these precursors on memory or other aspects of cognition, either in unaffected people or in patients with AD. The reason for this failure appears to be that precursors do not substantially affect the rate of cholinergic transmission even though they may increase acetylcholine concentrations.

With the help of a program project grant from the National Institute of Aging, as well as support from the Veterans Administration, my colleague Richard Mohs and I began a study of physostigmine in AD. We first administered an intravenous form of the drug and then an oral preparation. The inital studies with intravenous physostigmine were encouraging, although the ability of physostigmine to improve memory was hardly as robust as one might have hoped. Still, additional studies were necessary, because intravenous physostigmine is so short acting that it was impossible to adequately assess whether the drug would help patients in daily life.

Studies with oral physostigmine have begun. The drug is given every 2 hours from 7 a.m. to 9 p.m. in doses of 0.0, 0.5, 1.0, 1.5, and 2.0 mg each for three to five days. On the last day, the patients' overall symptoms are rated with the Alzheimer's Disease Assessment Scale (ADAS) at each dose. This instrument, developed in our laboratory, measures all of the principal symptoms associated with AD including memory loss, dysphasia, dyspraxia, agitation, and mood disturbance. The dose of oral physostigmine associated with the least severe symptoms is then randomly readministered along with placebo for three to five days under double-blind conditions.

Of the first 11 patients who completed this study, 10 showed some decrease in symptoms with at least one of the physostigmine doses. Of those, eight less severe symptoms while receiving physostigmine in the replication phase of the study than they did while receiving placebo. From a clinical perspective, only three of the patients demonstrated enough improvement to be clinically relevant. On the ADAS these patients showed at least a 10-percent improvement over placebo. However, there is very good reason to believe that not all patients with AD will respond to this drug, nor will all patients who respond to physostigmine respond in the same way. This problem arises from the fact that for physostigmine, which prevents the breakdown of existing acetylcholine, to work, the brain must be able to synthesize some acetylcholine. Unfortunately, as the disease progresses cells which synthesize acetylcholine are dying. Because of this problem we needed some way besides memory testing, to be sure the physostigmine was getting into the patients' brains. In collaboration with an endocrinologist in our laboratory, Dr. Bonnie Davis, we have found that when physostigmine enters the brain, and acetylcholine containing cells are available to synthesize adequate quantities of acetylcholine, the physostigmine increases the amount of cortisol the patient's body secretes at night. The effect of physostigmine to increase nocturnal cortisol concentrations correlates with the drug's ability to improve the symptoms of AD, as the figure below indicates. These results support the notion that physostigmine only improves the cognitive functioning in those patients whose acetylcholine containing neurons have not yet been devastated by the disease.

Although these results are encouraging to the scientist, for the patient with AD the effects are not as impressive or uniform as one would desire. Instead, they only point to other directions that must be pursued and better drugs that must be developed. Nonetheless, these results with oral physostigmine, which have been replicated in at least five other laboratories, indicate that current approaches are rational.

Given these effects of physostigmine, as well as results from other researchers, there is now need to identify those Alzheimer's patients who may be made modestly less demented by therapies that increase brain acetylcholine. A cooperative study has been proposed by Richard Mohs and myself, as well as medical scientists from a number of other VA's to determine the ultimate clinical utility of physostigmine. We are hopeful that it will be funded, and over the next five years, may be able to ascertain just what segment of the Alzheimer's population may be benefited by physostigmine. Such a study can only be done through the cooperative studies program at the Veterans Administration. The cooperative studies program has produced invaluable studies on the effects of treatment of high blood pressure, and prostate cancer, yielding information which has saved lives, prevented disability, and saved health care dollars.

Whatever the results of the studies in progress, it is clear that not all patients are going to be helped by physostigmine treatment, and that those patients who are helped will not be returned to normal life. For that reason, additional work is necessary. To that end, our program has been engaged in developing an "animal model" of Alzheimer's disease that may expedite development of other drugs. These studies are made possibly by a merit review grant from the VA to me and my collegue, Dr. V. Haroutunian, as well as collaboration wth the Hoechst Roussel Pharmaceutical Corp. Together we have found that destruction of a tiny part of the rat's brain can produce a deficit in acetylcholine that in many ways resembles the deficit that exists in AD. This rat model makes possible the screening of drugs for their ability to improve the memory of "demented" animals. We are particularly encouraged by one compound that increased both ACh and NE, another neurotransmitter deficient in some, but not all AD patients. This, and other promising compounds are now being tested in toxicological studies preparatory to human investigations.

The figure below illustrates how physostigmine, the drug we are administering to humans, can reverse the abnormal behavior that animals with a cholinergic deficit exhibit. Other drugs such as oxotremorine and 4-aminopyridine, are equally effective at normalizing these animals.

In the future, and with the help of the NIA's ADRC, new drugs that might be more efficacious will be tested, and more importantly, the model will be extended so that it even more closely resembles the human condition. Other neurotransmitter and neuromodulator deficits, particularly of noradrenergic neurons and somatostatin concentrations, will be induced. In addition, with the help of funding from VA and the NIA, we are now transplanting brain tissue to these lesioned animals in the hope of normalizing their behavior. This will be a difficult process, but one with obvious implications for developing a treatment for Alzheimer's disease.

A major thrust of research in Alzheimer's disease is the delineation of factors associated with an increased risk for the condition. To date, the single parameter repeatedly associated with an enhanced risk of Alzheimer's disease is a family history of Alzheimer's disease. Recent work conducted at Johns Hopkins has particularly supported this claim. Among first degree relatives (mother, father, sister, and brothers) of Alzheimer's disease patients, the incidence of Alzheimer's disease approached 50 percent in those relatives surviving to age 90.

The peak incidence of Alzheimer's disease occurs between the ninth and tenth decades of life. Thus, the majority of Americans do not, yet, live through the entire age of risk for the disease. Consequently, determining the heritability of Alzheimer's disease is made extremely difficult by the fact that most relatives of patients do not live long enough to definitely express, or not express, the disease. Advances in epidemiological and population genetics have made possible the use of mathematical techniques to correct for this problem, and facilitate a more accurate determination of the "genetics" of Alzehimer's disease. Results from our study, in which 244 first degree relatives from 50 Alzheimer's patients were studied, appears in the figure below. Like the Hopkins study, our work also indicates that genetics play a very strong role in the expression of this disease.

The possibility that genetic factors strongly influence the expression of Alzheimer's disease poses a new and exciting challenge to the Alzheimer's disease research centers. The extraordinary advances that have taken place in the last decade in molecular biology, including the cloning of genes, transfer of genes and isolation of gene products, can now be applied to Alzheimer's disease research. At this point, it is impossible to even guess at the discoveries that will derive from merging the powerful techniques of molecular biology with neurobiological methods presently being employed to elucidate Alzheimer's disease. However, the full marriage of these methods, which occur in the ADRC's, will require additional and perhaps unique modes of funding. Too often, traditional neurobiologists doing Alzheimer's disease research can conceptualize the molecular approaches that are needed in Alzheimer's disease research, but are not adequately familiar with the methodologies to present a credible proposal. On the other hand, molecular biologists are not adequately familiar with clinical and basic neurobiological issues to conceive of the use of their techniques in diseases like Alzheimer's. Thus, I would propose providing incremental funding (perhaps 20 percent) to each of the Alzheimer's disease centers simply for the purpose of recruiting to the centers molecular biologists with a commitment to apply their techniques to research in Alzheimer's disease.

This concludes my statement, I would be pleased to answer any questions that you or members of the committee may have.

Mr. RINALDO. Dr. Feldberg.

STATEMENT OF DR. MURRAY FELDBERG, COORDINATOR, ALZHEIMER'S DISEASE PROJECT, VA MEDICAL CENTER, LYONS, NJ

Dr. FELDBERG. Mr. Chairman, and members of the committee, I welcome this opportunity to discuss our program for Alzheimer's disease patients at the VA Medical Center in Lyons, NJ. In addition, I will attempt to indicate those areas that are in need of support in the future.

Mental decline associated with, but not limited to, old age is known by the term "dementia," or "chronic brain syndrome." The most common dementias are, one, the multi-infarct dementia caused by a series of strokes, which results in the death of brain tissue, and two, the so-called Alzheimer's disease which also leads to atrophy of the brain.

The symptoms of dementia include the following:

(A) a loss of intellectual abilities of severity sufficient to interfere with social and occupational functioning;

(B) memory impairment;

(C) and one or more of the following: impairment of abstract thinking as manifested by concrete thinking, difficulty in defining words, and difficulties with other similar tasks; impaired judgment; other disturbances of higher brain functioning such as difficulty in speaking, or aphasia; inability to carry out various activities despite the absence of paralysis, or apraxia; and failure to recognize or identify familiar objects despite intact senses, or agnosia;

(D) the patient is not delirious and, therefore, is aware and alert despite the confusion.

The above list of characteristics of dementia is taken from the Diagnostic and Statistical Manual of the American Psychiatric Association. The symptoms that occur most frequently include: serious forgetfulness, confusion and certain other personality changes, and behavioral changes.

These symptoms can be caused by a variety of organic conditions, some of which are reversible or, in other words, curable. Therefore, early diagnosis is essential. Alzheimer's disease is a chronic neuropsychiatric disorder of unknown origin and is characterized by impaired and deteriorating intellectual functioning.

When originally described in 1906, the condition was thought to be relatively rare, but the availability of refined diagnostic techniques has led to the awareness that the condition is much more frequent than originally thought. One study has shown that 20 percent of women and 8 percent of men in geriatric hospitals have this disorder. The condition may go undiagnosed because of its similarity to other neuropsychiatric disorders. Alzheimer's disease results in changes in the nerve cells of the brain's outermost covering, the cortex, resulting in the death of large numbers of cells. It is expected that over the next 50 years, the over-65 population will grow by more than 150 percent from 25 million to a projected 65 million in 2030. An estimated 6 percent of that population will suffer from Alzheimer's disease.

Alzheimer's disease accounts for over half of all cases of senile dementia. While Alzheimer's disease is characterized by: forgetfulness; impaired judgment; inability to handle routine tasks; lack of spontaneity; lessening of initiative; disorientation of time, place and eventually of person; the following must also be ruled out, since any of these conditions may cause a person to display Alzheimer's-like symptoms: pernicious anemia; medication reactions; hormonal problems; psychological conditions, especially depression; alcohol and other drug abuse; brain tumor and head trauma; chronic brain and meningeal infections; strokes, multi-infarct dementia; Pick's disease; Parkinson's disease; Creutzfeld-Jakob disease.

One may divide the course of the illness into four stages. The first stage, lasting from 2 to 4 years, is characterized by memory loss, disorientation, and a lack of spontaneity. Judgment begins to suffer and is often accompanied by a serious inability to handle everyday tasks.

The second stage, lasting many years, is characterized by progressive memory loss and difficulty in speaking, performing everyday tasks and recognizing familiar objects. There is a tendency to wander off and get lost, and to perform repetitious movements, such as lip-smacking or chewing. Most people with this condition, at this stage, are in constant motion. Although this phase is initially associated with an increase in appetite, later on there is a complete indifference to food and the patient even forgets to eat. Speech becomes slower and there is increased difficulty in making decisions and plans. The patient becomes increasingly self-absorbed and insensitive to others.

During the third stage, there is a marked change in behavior, with little warmth toward loved ones. People are misidentified. Finally, during the final phase of the condition, the patient is apathetic and incontinent, and must have total nursing care for even the most rudimentary task of daily living. Such is the course of the illness.

I would like next to describe the VA Medical Center at Lyons and then discuss the role we currently play in the care of the Alzheimer's disease patient and the role we would like to play in the patient's care, if we receive the appropriate support.

The Medical Center at Lyons is a 1,171-bed neuropsychiatric facility operated by the Veterans' Administration for the care of veterans primarily from New Jersey, but also from the neighboring States of New York and Pennsylvania. It is part of Medical District 4, which includes VA hospitals in New Jersey, Delaware, and Eastern Pennsylvania.

The facility is constructed in the form of two circles. Circle II is devoted entirely to the care of psychiatric patients. Circle I is dedicated to the care of the medically infirm veteran. It consists of 30 acute medical beds, including an intensive care unit and respiratory care unit. In addition, there is a rehabilitation medicine service consisting of 30 beds; 245 beds are given over to the chronic medical patient. There is a nursing home care unit of 90 beds and on October 17, 1985, ground was broken for the construction of an additional 240-bed nursing home care unit.

Within circle I, there are 38 beds designated for the care and treatment of patients with Alzheimer's disease and related dementias. The unit, called 9–A North and South, is staffed by two internists, 8 RN's, 1 LPN, and 21 nursing assistants. I am the coordinator of the program and also serve as the psychiatric consultant.

The unit is staffed around the clock, 24 hours a day, 7 days a week. Because it occupies the space formerly devoted to respiratory care, the unit is unusually well-equipped to handle medical emergencies such as aspirations, choking, and pneumonias, not to mention seizures and cardiac emergency. Because our patients, without exception, have multiple and severe medical problems in addition to Alzheimer's disease, the availability of expert medical care is essential.

Although the medical center had once hoped to be able to provide services for veterans who were in all stages of dementia, and indeed, to provide diagnostic evaluation for outpatients, recent changes in the resource allocation methodology have meant a curtailment of these essential plans. A program for outpatients consisting of a 5-day diagnostic workup has been set aside as impractical in light of current financial limitations. Because of the shrinking funds, the medical center has determined that it must limit its services to those veterans who are too disturbed or require such excessive amounts of care that they cannot be placed elsewhere.

Thus, the medical center is in the process of transferring patients who are located elsewhere in the medical center to the specialized program of the Alzheimer's unit. There are approximately 39 patients within the medical center who carry the diagnosis of Alzheimer's disease, although it is not clear to us at this point that all of them require the total care ward 9-A provides. Those who do will be transferred to the Alzheimer's disease unit. In addition, the medical center provides ongoing support and counseling for the families who are approaching the point of referral for admission to the medical center. These groups, heavily attended, meet monthly at the medical center during evening hours.

The medical center sees its responsibility as not only the care of the infirm Alzheimer's disease patient, but to support, within the limits of its resources, the significant research in the disease currently in progress at the VA Medical Center in the Bronx, and described by Dr. Davis in his presentation. The medical center also is currently involved in investigations into the symptoms of agitation and depression commonly found in Alzheimer's disease and the cause of significant failure in placement outside of the hospital.

Although the unit seems to be well-staffed due to the commitment of the chief of staff and medical center director, there are fundamental difficulties that stand in the way of care for these difficult patients. These problems cannot be resolved by cannibalizing the medical center. These patients, requiring as they do total care and constant supervision, make it mandatory to increase nursing personnel on all shifts. In addition, there is the planned essential ingredient of being able to provide timely intervention when the disease first appears since it is only then that reversible causes can be treated. It has been our hope to increase our involvement with the Alzheimer's disease patient by establishment of various outpatient diagnostic and support services. However, for the time being, this effort must be abandoned pending recognition by VA of the medical center's needs if it is to undertake the care of this most challenging patient.

In summary, then, Alzheimer's disease is an illness that may best be understood in terms of, one, its devastating clinical consequences for the patient; two, its impact on the family; and three, its impact on society. Because of the nature of the illness, there are numerous problems facing families who are attempting to cope with Alzheimer's disease patients. These behavioral and mental problems include depressions and delusions, and wandering and agitation and the stress on families is enormous. But even where these symptoms are not present, the retreat of the patients from contact with family members and the gradual inability of the patient to respond to affection and warmth takes its toll on the caregiver. Finally, the potential impact on society both in terms of providing alternatives to institutionalization such as respite care and partial hospitalization and the facilities for long-term care are enormous.

Thank you.

Mr. RINALDO. While you are there, if I may, do you believe the medical profession as a whole is up-to-date on Alzheimer's?

Dr. FELDBERG. No.

In conjunction with Mount Sinai and Bronx, we are having a series of seminars beginning at the end of November.

Mr. RINALDO. Do you think that the increased awareness of the disease, with that awareness, a more accurate diagnosis can be made by the physician?

Dr. FELDBERG. Yes. The diagnosis of the Alzheimer's picture is often based on a suspicion of senility and therefore what can be expected? I think that other diseases, which are themselves reversible, can be detected, and possibly corrected if caught early. As I said, we hope to begin the seminars at the end of November.

Mr. RINALDO. Dr. Davis, if I may, you suggested in your testimony recruiting molecular biologists and integrating them into the existing centers of excellence. Would this require legislation? Could the centers do it now on their own? Would it require funds?

Dr. DAVIS. Centers cannot do it now. The reason they cannot, the initial allocation to the 5 centers was for 5 years, each with a direct and indirect cost of about $700,000 per year. As it turned out the applications well exceeded in scope what could be funded by that $700,000 per year per center.

By the nature of the competition, the centers wrote relatively conservative applications. No center desired to engage in high-risk research with the possibility of not being funded.

Today, there does not exist in any of the centers the kind of flexibility that a director can recruit as outstanding molecular biologists, bring them into the center and equip their laboratories.

It is extraordinarily expensive to fund an entire laboratory in molecular biology.

Mr. RINALDO. If we were able to obtain the funds, would you be willing to work with the committee in coming up with a method of implementing your proposal?

Dr. DAVIS. I would be pleased to do that.

Mr. RINALDO. Either one of you: How early in the course of this disease, under current conditions, can a reasonably accurate diagnosis be made?

Dr. DAVIS. Diagnosis is a problematic issue in the disease. Until recently, rather loose diagnostic criteria were used almost internationally, which resulted in misdiagnoses rates that could be as large as 50 percent, when diagnoses in life was compared to the pathology at autopsy.

In the last few years, there have really been tremendous advances in stipulating clinical diagnostic criteria. I am aware of three studies which have used NINEOS criteria or criteria very much like them, and confirmed their diagnosis in life with post mortem changes. An accuracy of about 90 percent has been found.

To be that accurate, patients usually have to have had the disease 1 or 2 years.

Mr. RINALDO. Assume the patient has it for 1 to 2 years and it is accurately diagnosed, at that point in time, can anything be done to inhibit the progression of the disease? I assume that in one or two years, the disease should be at a relatively early stage.

Dr. DAVIS. At this point, there is nothing that can inhibit the course of the disease. Another interesting possibility raised by genetic studies, in combination with findings from position emission tomography, is that a diagnostic marker for AD that can be obtained with a PET scan. There is a PET scanner at Brookhaven where we collaborate.

Using that PET marker, it may be possible to identify a group of incipient Alzheimer's patients, patients who are perhaps showing pathophysiological changes on the PET scan.

If we could identify such a group of patients, it might be possible to begin to conceive of strategies of prevention. The difficulty here, again, is dollars. A complete PET scan facility costs approximately for $2½ million, about.

There is one facility in Brookhaven for our area, and that cannot really support the scope of research we envision.

Mr. RINALDO. What do you think should be an appropriate level of funding for research? I am on the Energy and Commerce Committee, which has jurisdiction on health matters, and this is something we discussed recently, when considering a piece of legislation, and I would like your opinion.

Dr. DAVIS. As you know, this is a very difficult question. There is no linear correlation between dollars spent and advances in science.

Certainly, the war on cancer has been prototypical in emphasizing the difficlty in relating dollars to results. We have an additional problem in Alzheimer's, as there are a limited number of centers of excellence. This is a disease which only recently attracted scientists. We have to pull ourselves up by our bootstraps.

In the past 2 to 3 years, there have been so many important advances in neurochemistry, neurophysiology, if we doubled the amount of funds, if we had $100 million today, it would be well spent.

This additional increment of nearly $50,000,000, to be optimally spent, will require novel funding mechanisms. Specifically, devices should be developed that could encourage collaborations between molecular neurobiologists and clinical neuroscientists. It is my firm conviction that the next breakthrough in Alzheimer's disease will require the application of a basic molecular strategy. Unfortunately, the majority of neuroscientists presently conducting Alzheimer's disease research are not primarily educated in molecular neurobiology, and those scientists who have their primary training in this area rarely conceptualize their investigations in terms of pathophysiological questions.

To facilitate the collaboration between these two groups, I would propose that the Alzheimer's Disease Research Centers apply to the NIA for funds specifically for the purpose of recruiting molecular neurobiologists to the Alzheimer's Centers. Three to five page preliminary proposals would be sent along with the curriculum vitae of scientists who would join the center. The NIA would provide equipment, salary, and technical support for approximately 3 years. At the end of this time it would be expected that the Alzheimer's Center would write a formal proposal for continued resources.

Obviously this is simply an outline of one of a number of possibilities for encouraging new directions in Alzheimer's disease research.

Mr. RINALDO. During the testimony of some of the other witnesses, they talked about Medicare and Medicaid reimbursement as a viable method of financing care of Alzheimer's victims. Can you give us an estimate or guesstimate of what this would cost nationally?

Dr. FELDBERG. No.

Dr. DAVIS. When we have talked about this in our laboratory, it is frightening. We have data with projections of the number of Alzheimer's patients in the United States by the year 2005.

Mr. RINALDO. What does that show?

Dr. DAVIS. Something over 2.5 million patients. This number really reflects the population of Americans who will be suffering from dementia of any kind. The percentage with Alzheimer's disease will be between 40 percent and 60 percent of this larger amount, with other causes of dementia being multi-infarct dementia as well as mixed cases of multi-infarct and Alzheimer's type dementia.

Mr. RINALDO. How many?

Dr. DAVIS. 2.5 million.

Mr. RINALDO. Can you give us an idea of what it would cost to Medicare?

Dr. DAVIS. If $40,000 is a fair number, we can project.

Mr. RINALDO. Per year?

Dr. DAVIS It is extraordinary. The country cannot afford this type of expenditure.

If we are not going to force you to make some awful decisions, to force you to make truly inhumane decisions, that we as physicians cannot face, we have no choice but to invest in research, though there is hardly a guarantee that it will work.

Mr. RINALDO. From your testimony, it seems to me that it would be almost impossible to fund that under Medicare because it would bankrupt the system. Additional research dollars in the magnitude of $100 million, those may provide more meaningful insight into the causes, possible causes of Alzheimer's?

Dr. DAVIS. Yes, and I would add a caveat. I think we might have to consider using that money in more unique ways than traditionally used by the Institutes. For example, different funding devices to begin to bring people together who would not otherwise come together and write a proposal.

How do we stimulate proposals from people who would not initiate them.

Mr. RINALDO. Your help in that area would be valuable to the committee as well as the Committee on Health, Subcommittee on Health, full Commmittee on Energy and Commerce.

Any ideas that you have and would like to offer, we would appreciate receiving.

Dr. DAVIS. Thank you.

Mr. Courter. Dr. Feldberg, is there any uniform treatment of veterans that have Alzheimer's disease across the country? How do you determine who you take? Is that first-come, first-serve? Are some VA hospitals taking Alzheimer's patients and others not?

Dr. Feldberg. I am not sure there is a uniform policy. I know that at Lyons there are multiple ways for a patient to enter a hospital.

There are patients who have made application to be admitted directly to the program. It is not really a program, but a ward that has been designated to house AD patients.

Usually, the patients are admitted almost on an emergency basis, and they will be admitted at all hours, including, well, when traditionally we are not available. That would be evenings or weekends.

Then, depending on where they are admitted, a consultation request is made of the Alzheimer disease group. We will see the patient and transfer them.

We have no policy other than that anyone who needs admission can get into the hospital. If they require intensive enough nursing care, they can be transferred to our ward.

We are stuck with a problem that our patients have to be totally disabled or have major behavioral problems in order for us to take them on 9A—the Alzheimer disease unit.

That is not a bad situation, because the hospital as a whole is geared to the care of chronic patients, but we feel there is a special type of care derived on 9A that can't be derived from others.

I think all VA hospitals suffer from the same burden, because of the changes effected by the resource allocation model.

Mr. Courter. You have 38 beds?

Dr. Feldberg. Yes. Designated for this project. We have 22 patients. All of our beds are taken. We have 22 patients that we call total care. They need assistance and not supervision; assistance includes eating, getting up, swallowing.

Mr. Rinaldo. You said that you have 38 AD victims in the hospital.

Dr. Feldberg. On our unit.

Mr. Rinaldo. Do you have a waiting list?

Dr. Feldberg. Not in the sense that you would think of one. We do not have a waiting list.

Mr. Rinaldo. Suppose there were another Alzheimer's patient totally disabled, could he be admitted?

Dr. Feldberg. Yes. The remaining beds, 16 beds, are occupied with patients in various forms of dementia who are not total care patients. We exchange in that instance.

We also discharge patients from the unit. There are patients who settle down who can return home.

There are patients who settle down and go to nursing homes. We have an active program in that regard.

Mr. Courter. I assume there is no answer to this question, but what is the life expectancy of somebody who contracts AD?

Dr. Davis. I think the statistics show the average length of illness is about 7 years, with a wide variation.

Mr. Courter. I would imagine the statistics show that if you contract at 72, you can live 7 years. If you contract at 55, is this a relationship or is it based on the severity of the disease?

Dr. DAVIS. The disease is more malignant and pervasive in younger people, with a more rapid downhill course, than a person who contracts the disease at 89, say.

Mr. COURTER. I believe you and others mentioned that heredity might have something to do with that. Is that accepted, an accepted understanding in the medical profession or is that theory?

Dr. DAVIS. I think what is accepted is that heredity plays an important role. The question is how important.

The data from our laboratory and Hopkins and work ongoing at Cornell would indicate extremely important.

That is why we have a new road to take, molecular biology.

Mr. COURTER. I believe you heard Mr. Phillipson testify. There was mention of a shunt operation. Is there anything to that? Is there any other type of operation?

Dr. DAVIS. Well, there are two possible surgeries that I talked about: one, that the disease was being misdiagnosed and that his wife had normal pressure hydrocephaly.

There is a group of neurosurgeons inserting an abdomenalventricular shunt, the shunt contains a drug which increases acethylcholine activity in the brain.

What that points out is the heroic measures that a neurosurgeon can conceive of to get drugs into the brain. A better way is to convince drug companies to develop better drugs, in order to get drugs to passed the blood-brain barrier.

Mr. SAXTON. Two questions for Dr. Davis, and I will ask the questions and let me explain why I ask them.

Do you consider Alzheimer's to be a form of mental illness? Second, if you do, do you feel that there is some measure of benefit to be gained by doing Alzheimer's research in conjunction with other types of mental illness research?

The reason that I ask the question is that I have learned that through research in various programs, certain types of advances can be made in treatment and administration of medication, almost as kind of a biproduct of one program into another.

Certain types of depression are helped or treated by drugs developed for the treatment of epilepsy.

If you consider this to be a type of mental illness or disorder, is the answer to the second question, then, one that would be important?

Dr. DAVIS. Well, in Europe, and the United Kingdom, psychiatrists traditionally take care of patients with dementia. In the United States, that has been less clear. Often it is neurologists, sometimes internists, sometimes psychiatrists.

That is perhaps because of an older tradition in American psychiatry of psychoanalysis.

In the past 20 years, more modern academic psychiatry is biological.

In fact, we are moving to consolidated departments of neurology, neurosurgery and psychiatry at Mount Sinai.

People with dementia have a behavioral disorder. Behavioral disorders can have an origin in chemical disturbances, or physical disturbances, but are the province of people interested in behavior. Such people should be working together and not split hairs.

We have learned in our group, as people who are very interested in depression and schizophrenia, a number of things about those diseases from studying patients with dementia.

There are collaborative synergistic effects that come from perceiving these diseases as having a common origin.

Mr. SAXTON. Our appropriation process is a reason for asking the question, in terms of what we can determine about Alzheimer's.

Dr. DAVIS. As an observer of some of the institutes, I think NIH has taken a lead to a degree in conceiving the Alzheimer's problems. I don't think it would be a bad idea if you used as the lead agency NIA in funding research.

Mr. RINALDO. I would like to thank our witnesses.

Before we leave, I was intrigued by your statement that much more can be done, Dr. Davis, if private industry spend additional funds in research. Is there any way that you know of that we can encourage this to take place?

Dr. DAVIS. Yes. I am not a great advocate for the idea that pharmaceutical companies should reap huge returns from research. But the cost of conceiving an Alzheimer's project from synthesizing a drug to FDA approval has been estimated by some individuals that I have met, whom I respect, as $100 million. That is an extraordinary cost.

Because of that cost, it is a very rare company that will take a high risk approach. The result is a lot of me-too kind of pharmacology, of taking a drug that is approved and is very, very modestly effective in some studies and devising a new analog of it. That approach is not so expensive or fraught with risk.

Drug companies may need an added incentive in diseases like Alzheimer's, where the risk is great.

I repeatedly gave detailed scientific discussions to a number of conferences where pharmaceutical manufacturers were there. I was invited to address the Pharmaceutical Manufacturers Association meeting, and virtually every major U.S. pharmaceutical company was there, and when it was over, only one came back to me and said this is interesting and let's see if we can conceive of a project that might alleviate suffering.

Most companies feel it would be safer to synthesize analogs of existing compounds.

Perhaps that is because of the patent laws and they should get larger return for $100 million profit. I cannot speak to that.

Mr. RINALDO. Thank you. You have provided valuable insights into the disease. Thank you for your exceptional help to the committee.

I would like to once again thank my colleagues, Congressman Courter and Congressman Saxton, for joining us in this productive hearing.

We will bring this information back to the other members of the committee in Washington, along with the rest of the committees that deal with this problem. Hearing adjourned.

[Whereupon, at 12 noon, the hearing was adjourned.]

APPENDIX

PREPARED STATEMENT OF MARYANNE BENSON, BOARD MEMBER, ALZHEIMER'S DISEASE SUPPORT NETWORK, NEWARK, NJ

I am the daughter of an Alzheimer's victim and aware of the devastating effect of this disease on families. My mother, a victim of Alzheimer's disease, has been living in a nursing home since 1983. Since my father passed away, I am personally and financially responsible for her care, but I could not financially afford her nursing home care without Medicaid assistance.

It has been one year since the State of New Jersey addressed the issue of Alzheimer's Disease with the establishment of an Alzheimer's Disease Study Commission. That concern has developed into a commitment from the State to appropriate $500,000 to set up the Alzheimer's Institute at the Community Mental Health Center at Rutgers Medical School. This Institute will begin to address some of the concerns of families with its diagnostic and resource center and professional training component. This Institute was realized through the joint efforts of public officials, professionals and family members. Family members, through the support group network, have played a key role in this partnership and should be recognized for their lobbying efforts.

I have been active with professionals and caregivers in family support efforts and have seen the commitment and dedication from these families. It is through the support group network that patient management and practical concerns are shared, issues discussed and information exchanged. Support groups play an important role in the dissemination of information to both caregivers and professionals. The support group network is an integral part of this partnership. Professionals and public officials can be more responsive to some of the problems facing the patient and family by working through the support group network.

With the national attention that Alzheimer's Disease is receiving, I hope that more resources will be channeled into the fight against it and that New Jersey will be in the forefront of this fight.

MILLTOWN, NJ, *October 28, 1985*

To whom it may concern: The need for improving medical care and special facilities for Alzheimer's victims is a national priority! All hospitals and nursing homes should have trained personnel that are familiar with the disorder. The majority of these patients when they become end stage (that is totally dependent on others for their care), and become medically ill, require around-the-clock medical attention which general nursing homes cannot provide because of inadequate facilities.

National health care dollars, especially Medicaid should be available to all without restrictions of time limitations in relationship to the onset of the disease versus the time a medicaid application was submitted for the patient. Unless you are completely destitute for a period of 2 years prior to the onset of this disease, you are not eligible for benefits from Medicaid, and the hassle, aggravation, and humiliation from all the local agencies is involved with your application is just a waste of time! There is a great need to restructure this system so honest people, taxpayers, can receive some Federal aid.

Finally, a program for minimally afflicted patients should be made available for assistance at home in order to allow only more severely affected patients in the hospital setting. The need for support groups that tell it like it is are also in real demand since this disease devastates and completely wipes out the entire family. Please help, you all might suffer from this horrible disorder some day in the near future. Alzheimer's knows no age limitations or cares about what you did for a living. It destroys you painfully slow or kills you in six months. We need help, before it's too late. Thank you.

SOPHIE GROCHMAL

SUMMIT, NJ, *October 19, 1985.*

Congressman MATTHEW J. RINALDO,
Union, NJ.

DEAR CONGRESSMAN RINALDO: Thank you for calling the above reference hearing and so advising me. I will be unable to attend however would like to share my feelings and suggestions as to how my husband and I have been dealing with his brother who has been diagnosed with Alzheimer's disease. I am hopeful that some of my comments might help others, and please feel free to utilize any at the hearing.

(a) Gain as much knowledge as possible germaine to this form of organic brain disorder. This can be attained by joining a support or self-help group for families and caregivers. In our State of New Jersey we are fortunate to have the New Jersey Self-Help Clearinghouse which can provide Alzheimer's self-help group information in just about every county. I have enclosed a folder regarding the clearinghouse. Also many hospitals have ongoing professionally staffed support groups which can be of great assistance as they can guide one in coping on a day-to-day basis.

(b) Explore the areas of day care programs for the Alzheimer person, if applicable with your physican. Such structural programs provide stimulation for the victim and respite for their caretakers.

(c) Avail yourself to counseling. This avenue is beneficial not only to the families acceptance of this devestating disease, but will provide them with a better insight and understanding leading to acceptance. Acceptance being a very difficult and personal area to discuss openly within a suppprt or self-help group of strangers until a mutual confidence and bonding is formulated.

(d) Communication within the family as well as friends and neighbors of this illness is essential. Do not hide the patient away from company—encourage visitors and conversation. If this positive attitude and mutual knowledge about the disease is shared no further explanation should be necessary to relay why the Alzheimer person does certain tasks either verbally or physical. Do not be ashamed or make excuses.

(e) If you are the primary caretaker, plan time with a friend to care for your own needs. Caring for an Alzheimer victim is much more than any 24 hour schedule for the average person. A caretaker needs some time to get away and then return refreshed to take on another day. Many Alzheimer's groups have visitation teams and this is so very important for the caregiver.

(f) Do not blame yourself for the illness that has befallen your loved one. If its course is rapid try to maintain and provide the patient with the same dignity and encouragement as existed prior to diagnosis. This is a very difficult task. Keeping a networking of persons with whom you can reach to for help is essential for both the caregiver and patient.

(g) The financial needs can in some cases be very overwhelming. Again seek professional help especially with regard to long term nursing care.

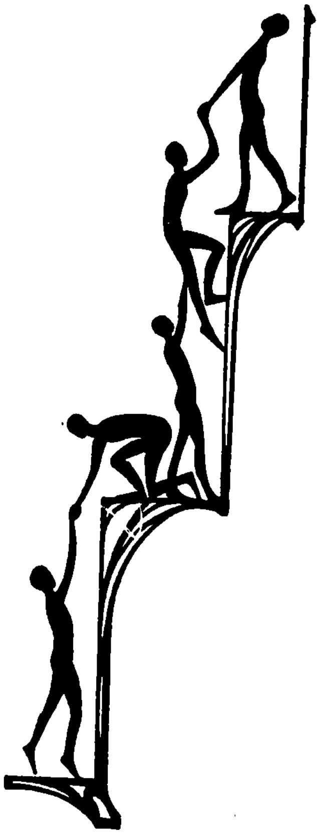
In closing Congressman Rinaldo, I would like to personally thank you and your congressional aide, Mr. Paul Schlegel, who responded to my inquiry regarding the status of your Alzheimer bill outlined in your June 1985 bulletin. If I can provide you with any assistance please feel free to contact me.

Very truly yours,

JACQUELINE M. SCHECHTER.

Enclosure.

NEW JERSEY SELF-HELP CLEARINGHOUSE



HELPING PEOPLE HELP THEMSELVES
through the use & development of
MUTUAL AID SELF-HELP GROUPS
1-800-FOR-M.A.S.H.
(that's 1-800-367-6274)
From outside New Jersey
201-625-7101

HAVE YOU EVER NOTICED WHEN YOU HAVE A PROBLEM . . .

how it helps to talk with someone who has had a similar problem? Simply finding others who have "been there" and finally realizing that "you are not alone" can in itself be a great relief. Self-Help groups do this and more. Members help one another in various ways by providing support and understanding as they share their experiences, strengths, hopes, fears, skills, practical information and encouragement.

WHERE THE FEELING IS MUTUAL

Self-Help groups can be better described as Mutual Aid Self-Help or **MASH** groups, because they derive their energy from members helping one another, without forms or fees. MASH groups are member-run, but in some cases are developed or assisted by professionals who remain "on tap" rather than "on top". Groups are voluntary, composed of peers, and typically meet in churches, community centers or members' homes, in an atmosphere that is friendly, compassionate and accepting.

OVER 3,200 GROUPS MEET IN NEW JERSEY AND...

they help people cope with hundreds of different stressful life situations and transitions - from overcoming an addiction or compulsion to coping with a serious illness or disability; from dealing with the loss of a loved one to learning new parenting skills or caring for an elderly parent. There are these and many more. But as many of these groups operate informally from "kitchen table offices", they are often not easily located.

TO LOCATE A GROUP THAT ADDRESSES YOUR NEED. . .

telephone the Clearinghouse toll-free at **1-800-FOR-M.A.S.H.** (Mutual Aid Self-Help) or **1-800-367-6274** weekdays 9 am to 5 pm. From outside New Jersey, dial (201) 625-7101. A quick computer search will provide you with information on groups in your area, or as needed, it will extend the search to adjacent counties, the entire state, or even to out-of-state group contacts.

TO INCREASE YOUR AWARENESS AND UNDERSTANDING OF GROUPS...

the Clearinghouse provides other services which inlclude: consultation to existing groups, workshops, speaking engagements, research projects, work with the media, periodic conferences, its NETWORK newsletter, the SELF-HELP GROUP DIRECTORY, and specialized service programs such as those to develop groups for visually impaired persons, as well as those to promote related church-based volunteer projects.

EXPLORING SELF-HELP GROUP OPPORTUNITIES - SOME REMINDERS

While the Clearinghouse seeks to maintain comprehensive listings, a few groups may have escaped attention. Omission of a group does not signify disapproval. Nor does provision of information on a group constitute an endorsement. Mutual help groups are not meant to replace needed professional services, although they often supplement and support them. While initial research reflects the value of such groups, the ultimate evaluation and very survival of any self-help group is determined by those who attend it.

JOIN WITH OTHERS TO START A GROUP

No appropriate self-help group in your area? Please consider the possibility of helping to start one - it is only after one person has taken that first step to express his/her interest in starting a group, that a group can indeed be started. You can call to register your interest. The Clearinghouse would then network or link any future callers, who share your concern and interest, with you.

YOU CAN DO IT...

but you don't have to do it alone. In addition to registering persons interested in starting groups, the Clearinghouse also can provide you with the most important of its services - free consultation on how you can go about starting a group. This includes our providing you with general guidelines, advice, ideas, helpful contacts, and other resource information that avoids your having to "reinvent the wheel". We emphasize "modeling mutual aid from the start" or involving others in the process so that the responsibility for starting and running the group is shared and does not fall on any one person's shoulders.

SELF-HELP GROUPS HELP...

and the Clearinghouse exists to help you both find and form such groups more easily. As the first statewide and computerized operation of its type in the country, the Clearinghouse has already assisted many dedicated persons in the development of several hundred new MASH groups throughout the state, some of which were the first of their type in the state and in the country.

THE MASH NETWORKING PROJECT

To meet the needs of an increasing portion of the New Jersey population suffering from a rare condition or illness, for which no self-help group exists anywhere in the country, the Clearinghouse has initiated the MASH Networking Project to help link persons nationally into new, first-of-their-kind, mutual aid networks.

If someone is interested in starting a mutual aid organization or network for a particular problem for which no group currently exists, the Clearinghouse will consider listing that person in its national database as a contact person; and will make referrals to him or her, to help start a mutual aid association via correspondence, telephone and/or computer networks.

Persons interested in forming such new MASH networks should contact the Project by calling (201) 625-7101 or writing the Project (please include a stamped, self-addressed envelope) at the address below. The MASH Networking Project will also link persons with any regional self-help clearinghouse or existing model groups that may be found in their area.

A NEW APPROACH TO HELPING PEOPLE HELP THEMSELVES

The Clearinghouse is sponsored by Saint Clare's Hospital and funded by various government, foundation, corporate grants and private contributions. We welcome your support and assistance in helping us promote the increased identification, awareness, understanding and development of Mutual Aid Self-Help resources.

NEW JERSEY SELF-HELP CLEARINGHOUSE
SAINT CLARE'S HOSPITAL
DENVILLE, NEW JERSEY 07834

A Sampling of Just Some of the Issues & Groups

Addictions/Compulsions:
- for alcoholics or their families
- Narcotics Anonymous
- Cocaine Anonymous
- for compulsive gamblers
- Overeaters Anonymous

Chronic/Physical Illnesses:
- Arthritis Clubs
- ADAPT (A Diabetic's A Person Too)
- Alzheimer's Disease Support
- Easy Breathers (respiratory)
- Stroke Clubs
- Multiple Sclerosis Self-Help
- Mended Hearts (heart surgery)
- various cancer groups
- Chronic Pain Outreach
- Make Today Count (life threatening illness)

Disabilities/Impairments:
- Eye Openers (visually impaired)
- SHHH (Self-Help for Hard of Hearing)
- In Step (amputation)
- Phoenix Society (burn victim)
- Speak Easy (for stutterers)

Loss of Loved One—Bereavement
- Compassionate Friends (death of a child)
- MIDS (Miscarriage, Infant Death, Stillbirth)
- SOS (Survivors of Suicide)
- various widowhood groups

Mental Health and related Support:
- Anorexia/Bulimia Support
- Emotions Anonymous
- Recovery, Inc.
- Agoraphobics Anonymous
- VOICES (Victims of Incest Can Emerge Survivors)
- Families of Mentally Ill

Parenting Concerns and Problems:
- Resolve (infertility)
- Microtots (parents of prematures)
- Cesarean Parents
- ABC (After Baby Comes)
- PEP (Parents Encouraging Parents of handicapped)
- Mothers of Twin Clubs
- CUB (Concerned United Birth parents)
- Single Parent Society
- Yours, Mine, Ours (Stepparents)
- Toughlove
- Families Anonymous (drug abuse)

Other Examples of Different Groups:
- PREP (Persons Responsible for Elderly Persons)
- Crime Victims
- Cult Awareness Network
- MADD (Mothers Against Drunk Drivers)
- Men's Groups
- Veterans' Groups
- Job Seekers (Unemployment)

Prepared Statement of the Institute for Alzheimer's Disease and Related Disorders

I. INTRODUCTION

Due to the advocacy of families of victims of Alzheimer's disease and related disorders through the Alzheimer's Disease Study Commission, and the response of Government representatives to their testimony; the Community Mental Health Center of Rutgers Medical School, University of Medicine and Dentistry of New Jersey, has been appropriated funds to establish an institute which will develop patient services, provide professional education and stimulate research initiatives. This institute will be developed by COPSA (the Community Outreach Program for Senior Adults), a unit of the Community Mental Health Center of Rutgers Medical School which has been delivering comprehensive mental health services to the elderly for over 10 years and is already well-known throughout New Jersey for its commitment and concern for families and professionals dealing with Alzheimer's disease.

II. GOALS

The goals of the institute will be:

(1) to maintain at their highest level of functioning in the least restrictive environment those persons suffering from Alzheimer's disease and other dementias.

(2) to reduce the impact of dementing illness on the families of victims through education, counseling, and linkage with community support.

(3) to expand and improve the network of services for persons with dementia and their families in home, community and institutional settings.

(4) to extend the knowledge base about the diagnosis and management of dementing illnesses to a variety of health-related professionals through training and research.

III. SERVICES

Proposed services will be provided in three components: A resource center, a diagnostic clinic, and a day program for cognitively imparied older adults. These components will function separately but will also be joined administratively and clinically into a comprehensive system dedicated to patient/family services and professional education.

(A) Resource center

The resource center will take primary responsibility for providing information, counseling, education and referral to families and allied health professionals. An 800 telephone number will provide ease of access to families and professionals statewide. Data about incidence and unmet needs will be collected, liaison will be established with service providers and family support groups throughout New Jersey, professional training programs will be developed, and educational materials will be made available.

(B) Diagnostic clinic

CMHC–COPSA staff will develop the diagnostic clinic in collaboration with Rutgers Medical School, Departments of Family Medicine, Neurology, and Psychiatry. It will provided: (1) comprehensive multidisciplinary evaluation to differentiate reversible from irreversible dementias, (2) treatment recommendations, (3) followup plans, and (4) referral. Initial evaluation will be done by a family medicine physician, a nurse, and a social worker, with additional evaluations provided by other specialties as indicated. In addition to providing clinical services, the diagnostic clinic will become a training site for medical and other professional students, interns and residents and will form the foundation upon which clinical and social research can be developed.

(C) Day program for congnitively imparied older adults

The day program will be a training site for hands-on professional education in effective management techniques and program design for dementia patients in a variety of institutional settings. It provides comprehensive evaluation, rehabilitation and monitoring for dementia patients as well as education, support, and case management for their families.

IV. CONCLUSION

The priority of the Institute for Alzheimer's Disease and Related Disorders will be to ensure excellent health and mental health services by competent professionals to the families of Alzheimer's victims whose advocacy has created this opportunity. The collaboration between various UMDNJ-RMS departments in developing the institute is an important step toward improved care for older persons. The multidisciplinary treatment and education model developed will provide leadership in meeting the needs of an expanding aged population in New Jersey.

PREPARED STATEMENT OF VISITING NURSE AND HEALTH SERVICES, ELIZABETH, NJ

My name is Rebecca Marvin and I am director of planning and development at the Visiting Nurse and Health Services which provides comprehensive home health care and public health nursing to 17 towns in Union County, New Jersey. I am here today representing Rosemary Cuccaro, executive director of VNHS. Mrs. Cuccaro has appeared before this august committee several times and regrets she cannot be here today.

I'm going to ask you each to use your imagination. Imagine that you are Jane Smith. Jane is 58 years old and works as a division clerk at a local factory. Jane is married to Jim, a 67-year-old retired blue collar worker. The Smith's have two children; their son, now living in Texas and their daughter, who lives near Trenton. Both childen are busy raising their own families and although they love and support their parents as much as they can, they cannot do much in the way of daily, ongoing support.

Jim was 59 when he first began to experience the early symptoms of Alzheimer's disease. However, he did mange to function well enough to work until he was 62 when he was forced into early retirement with reduced pension benefits. Jane has managed well during the last 5 years, by leaving lists and making frequent checkup phone calls while she was at work. Home and neighborhood remained a safe and healthy place for Jim to be. Now, however, it is no longer safe for Jim to be home alone for extended periods of time. Despite the systems Jane has instituted, he forgets to turn off the burners on the stove, he does not always dress appropriately for the weather and when he goes out, he doesn't lock the house and he sometimes forgets his way home on once familiar streets.

Jane is faced with a dilemma. Will she be forced to quit her job, thus giving up her pension (she has 2 more years until she is fully vested), and her health and dental benefits which cover both her and Jim—or will she be forced to put Jim into a nursing home. Jane has long ago accepted the loss of any personal or social life—but to be confined to home every day with Jim—even her strong commitment to and love for Jim could not replace the relief that working provides.

Then a friend suggested she call the Visiting Nurse. What is VNHS providing for Jane and Jim?

First, we sent a nurse and social worker to the home for a full health and socioeconomic assessment. In general, Jim's health is good, but Jane is experiencing frequent bouts of colds and flu and every other "bug" that goes around. The stress of caring for Jim is taking its toll.

Financially the Smiths would be secure if it weren't for the demands made by Jim's disease. Jane and Jim are above Medicaid and Medicare waiver guidelines, but clearly are not wealthy. They are part of that infamous lower-middle income class. Jim has Medicare benefits, but Jane's only health insurance is provided through her employer. If she quits, she won't have any health insurance until she reaches age 65—that's 7 years away.

VNHS is currently providing a home health aide for 2 hours, 3 days a week, and a neighbor looks in occasionally. Jim has been referred to an adult day care program and he is on a waiting list. Day care centers can't take too many Alzheimer patients, they require too much one-on-one supervision and reimbursement rates don't pay enough. Once a month, VNHS provides a respite companion, so that Jane can attend evening activities at her church, her only social outlet.

Who is footing the bill for this care? Not Medicare. Medicare only pays for "skilled care"—Jim's care does not meet criteria. Not Medicaid. The Smiths do not meet financial need criteria. Not Jane's insurance—it is designed for acute care episodes not chronic, deteriorating diseases.

Who then is paying? The Smiths pay as much as they can for the home health aide and nursing visits according to sliding scale fee schedules. A grant from the county pays for the respite care since the Smiths do meet title XX income criteria.

Is this care enough? For the moment it is holding Jane and Jim together. But the day is coming when it won't be enough. Jim really needs to be in a supervised setting where he can be involved in therapeutic activities such as current events, discussions and receiving socialization.

By spending down, Jim will qualify for nursing home placement in 2 years. But is a nursing home (if he can get a bed) really the right level of care for Jim? He does not need skilled physical care, he needs supervision, a companion, a "friend." The daily cost of a nursing home is approximately $76 per day. For much less than that. VNHS could provide care in an adult day care setting. We have designed a nursing-model program for cognitively impaired people but cannot secure funding. Again, Medicare will not pay for nonskilled services.

For about that same daily rate, we could provide 8 hours of homemaker services to Jim at home. Again, Mediciare will not pay—and neither will Medicaid. What then is the solution for Jane and Jim and thousands of others like them?

In the first 6 months of 1985, VNHS provided care to 18 patients formally designated as having Alzheimer disease. One patient paid full fee for care provided; two received care through title III funding; one has Medicaid; and three receive Medicare benefits for their care because, although Alzheimer's disease is the primary diagnosis, they also have skilled nursing needs such as catherer care. Perhaps we should put catherers in everyone—then they can at least get some limited care. Payment for care for the remaining 13 patients came from municipal funds and donations to VNHS including United Way funds. But this money is not enough to meet needs. It is not an unlimited supply.

Although 18 patients does not sound like many, for everyone who is receiving services there are likely two more patients and families who need care but are not eligible under existing funding sources. We never see these patients.

The solution is choices and resources. Choices of programs and services that complement the care that most patient's families are giving and have made a committment to. Choices of programs and services that enable the primary care givers to continue to give care services that permit the care giver to continue to work. Services that mean other family members will not be neglected and estranged from the primary care giver—services that enable the primary care giver to maintain their own physical and mental health. Choices of services and programs that enable the patient to be where he or she wants to be and should be. Choices that include a full spectrum of services—home care, respite care, day care, sheltered care, nursing home care. All of those are already available in Union County. But the second half of the solution, resources, have not been committed. The few resources that are available are scattered in different programs, channeled through different agencies and governed by different criteria with lets Alzheimer's patients fall through the cracks.

For example, 2 weeks ago, one Alzheimer patient was deemed ineligible for Medicaid because family income was to high. The patient was referred to the CCPED Program (Community Care Program for the Elderly and Disabled) but deemed ineligible because individual income was too low (ergo should be eligible for Medicaid).

A commitment of coordinated resources for choices means a spouse need not impoverish his or her own older years to provide care now. It means a family can keep a loved one at home, paying what they can afford to help supplement home care if they so choose, usually at a much lower cost than institutional care. Choices and resources—a humane solution.

Thank you for allowing us the opportunity of submitting this testimony and for taking the time to read same.

PREPARED STATEMENT OF FREEHOLDER ADRIANNE DAVIS, ESSEX COUNTY, NJ

Good morning. I am Freeholder Adrianne Davis, and I reside at 36 Hawthorne Place, Montclair, NJ.

I thank you for the opportunity to come before you today to talk about a very painful and devastating disease.

As a family member and specifically the daughter of a victim of Alzheimer's Disease, the most profound impact of this experience has been the fact that the family and the loved ones participate in the suffering. In short, everyone is affected. Also, in the case of my family, which I know is not unique, middle class people do not have the means to meet the medical expenses of an Alzheimer's patient. And while it would be totally insensitive to view this condition as merely an economic issue, it is my experience that, in many ways, it is the only part of the many dimensions of suffering which can be addressed.

For example, my father, who was unofficially diagnosed five years ago at the age of 62, had to be placed in a nursing home (and there was a lot of soul searching before my family and I came to this decision). Because my father worked loyally all his life like a good American, he received a pension and Social Security and therefore was not eligible for any financial assistance. What this translates into is the fact that my sisters and brothers and I must pay the nursing home costs which, at this point, amounts to $65 a day. My question: How long must we bear this burden alone?

And now I'll wear my other hat, not as a family participant, but as a public responsibility—I believe strongly that we need new laws and new regulations to help share the costs of this devastating disease. Indeed, I think it is in the public interest that we begin to meet this responsibility. I also believe that, in bringing this issue to the broader public, we will find more interest in finding ways to alleviate and perhaps cure this widespread problem. In other words, if we continue to keep the Alzheimer's problem merely the personal tradegy of families, we delay the day when we can meet this challenge head on. Putting it another way, when people have to pay the bill, they become more interested in the problem. Therefore, I believe it is important that we get the greater public concerned, and I commend your efforts in doing so.

And finally, on a personal note, I feel a deep commitment to participate with you in working towards measures which would help the victims and the families of Alzheimer's disease. Thank you.

○