

**ALZHEIMER'S RESEARCH AND CARE:
HELPING PATIENTS AND FAMILIES**

HEARING

BEFORE THE

SUBCOMMITTEE ON AGING

OF THE

**COMMITTEE ON HEALTH, EDUCATION,
LABOR, AND PENSIONS
UNITED STATES SENATE**

ONE HUNDRED SEVENTH CONGRESS

SECOND SESSION

ON

EXAMINING THE ISSUE OF ALZHEIMER'S AND THE ROLE THAT THE
COMMITTEE PLAYS IN THE REAUTHORIZATION OF THE LEGISLATION

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ALZHEIMER'S RESEARCH AND CARE: HELPING PATIENTS AND FAMILIES

TUESDAY, APRIL 2, 2002

U.S. SENATE,
SUBCOMMITTEE ON AGING,
COMMITTEE ON HEALTH, EDUCATION, LABOR, AND PENSIONS,
Washington, DC

The subcommittee met, pursuant to notice, at 10:10 a.m., at the Gerontology Research Center, Johns Hopkins Bayview Medical Center, Baltimore, Maryland, Hon. Barbara A. Mikulski [chairman of the subcommittee] presiding.

Present: Senator Mikulski.

OPENING STATEMENT OF SENATOR MIKULSKI

Senator MIKULSKI. Good morning, everybody.

The United States Senate Committee on Health, Education, Labor, and Pensions will come to order.

This is a hearing of the Subcommittee on Aging, of which I am the chairperson, and it is a field hearing on the issue of Alzheimer's and the role that the committee plays in the reauthorization of Alzheimer's legislation.

I am glad to be once again back at Bayview, where I visited in 1999. At that time, I said that I was very deeply troubled that the National Institute on Aging's budget was quite spartan, that it was close to \$600 million, when Alzheimer's is one of the most devastating chronic conditions to affect primarily older Americans.

At that time, the National Institute on Aging's budget was \$600 million. That was for the whole National Institute on Aging, including diabetes, cardiovascular disease, Parkinson's, and Alzheimer's. Alzheimer's research got \$323 million, and I knew that we needed more money to come up with more ideas on how to deal with both the issues of aging, health, as well as Alzheimer's.

At that time, I said to my constituents here that I promised to fight for more funding for the National Institute on Aging. I was not going to fight just for incremental increases; I said that I was going to work my earrings off to double the funding for the National Institute on Aging. Well, I have my earrings here; I worked them off. And I am happy to announce today that when we pass the appropriations bills this year, we will have doubled the funding for the National Institute on Aging.

I have a little saying, which is that "each and every one of us can make a difference," and I know that all of you in this room are already making a difference, from the researchers who are working

so hard on cures and cognitive stretch-outs to the advocates who speak up for the families of those with Alzheimer's to the caregivers as well as the public policy administrators. Each of you has made a difference, but we have all worked together on this change, and I believe that when we do work together, we do make change.

This year when we implement the President's request, the National Institute on Aging budget will be \$1 billion—\$1 billion. Alzheimer's research for this year will go from a little over \$300 million in 1998 to \$600 million. This is really a great victory, and everybody in this room has worked so hard, as well as your counterparts nationwide.

Now, this is not about money; it is really about mission. Doubling the budget for the National Institute on Aging is paying off. I took a tour this morning to see what the research looks like. Scientists have found evidence that a drug that is now used to lower cholesterol might prevent Alzheimer's. Researchers are testing a vaccine on mice that might also help deal with these issues.

There are currently seven clinical trials looking at whether estrogen, Vitamin E, and even aspirin might help to prevent Alzheimer's or prevent the onset of Alzheimer's, in other words, delay the onset.

Cutting-edge research demands cutting-edge facilities. When I took this tour 3 years ago, the building in which world-class research was going on was really a third-class building. World-class research needs world-class facilities.

So Senator Sarbanes, Congressman Ben Cardin and I teamed up with Hopkins to outwit the General Services Administration on how we could get you a new building faster, cheaper, and better-equipped on the drawing board. We won that victory, and next year, we are going to have a groundbreaking for a new facility that will mean better labs, better collaboration, and the ability to do better research.

So we now have the money, we now have the building, because we know that more needs to be done. Alzheimer's disease is a devastating illness. One in 10 people over 65 and nearly half of those over 85 will experience it.

The issue of family caregiving, on which I will be holding a hearing later on in the spring, means that caregiving families through their own family sweat equity really put into the economy. If caregivers were to be paid a wage for what they do for their own families, their spouse, their parent or whatever, it would come out to about \$196 billion of real sweat equity from the American people.

We need to get help to those who practice self-help, and not only breakthroughs, but cures and cognitive ability to stretch out and help for the caregiver.

So we will be hearing more about these issues as this hearing is going on.

I have recently introduced a bill to make sure that Alzheimer's families have the support they need, both in the lab and in the community. With Senator Kennedy and Senator Clinton, and also on a bipartisan basis, we have introduced legislation to be able to do this, to be able to improve the care of patients, and again, we will talk more about that.

But I want to listen to you now. Yes, I have fought hard for the funding for Alzheimer's research and care, because I understand what it does to families. My dear father had Alzheimer's. I have said that I watched my father die one brain cell at a time. My father was a very modest man, a hardworking man. He owned a grocery store just a few blocks from this building where we sit today. My father would not have wanted a big monument built to him, but he would have been very proud that the young lady that he sacrificed so much to send to school was out there to help other dads like himself. He and my mother raised me to be a fighter, to stand up for what is right, and I believe that the commandment of "Honor your mother and your father" is not only a good commandment to live by, but it is also a very good commandment to govern by. This is why I work so hard on issues affecting aging.

We used Bayview; we had the geriatric evaluation under Dr. John Burton. Dad used the Mason Lord adult daycare that was so important to both care for him and give my mother a bit of a breather. And then, as a very young social worker, I was also out here when Mason Lord and Mazie Rappaport, a social worker, were doing pioneering work.

Wherever pioneering thought was given and where compassion was linked with care and research, it was right here at Bayview, right here on this campus.

So we are very pleased to be here and be able to be an advocate and make sure that families that have worked hard all of their lives will have the opportunity to enjoy that life.

With that, I will conclude my remarks and turn to our witnesses.
[The prepared statement of Senator Mikulski follows:]

PREPARED STATEMENT OF SENATOR MIKULSKI

I'm happy to be back here at Bayview. The last time I was here was in June 1999. The National Institute on Aging's budget was spartan, just \$597 million. Alzheimer's research got just \$323 million. I promised to fight for more funding for the National Institute on Aging. Not just an incremental increase—I promised to double the funding.

I have good news to share with you. I've kept that promise. The National Institute on Aging's budget will be more than \$1 billion this year. That's double what it was 5 years ago. Alzheimer's research this year will receive more than \$600 million. It's a great victory because of the important work done here at Bayview.

Doubling the budget for the National Institute on Aging is paying off. Scientists have found evidence that a cholesterol-lowering drug may prevent Alzheimer's. Researchers are testing a vaccine on mice that may prevent the disease in humans. Seven clinical trials are currently underway to find out whether estrogen, vitamin E, ginkgo biloba, and aspirin help to prevent Alzheimer's.

This cutting edge research demands cutting edge facilities. That's why I fought, with the help of Senator Sarbanes and Congressman Cardin, to make sure NIA research will have a new state-of-the-art facility here at Bayview. A new facility means better labs, better collaboration by working together at central location, and a better chance of recruiting the best researchers from around the world.

Even with these victories, there is still a lot more to do. Alzheimer's Disease is a devastating illness. Four million Americans suffer from Alzheimer's, including one in ten people over age 65 and nearly half of those over age 85. Nineteen million Americans say they have a family member with the disease. The Medicare program alone spent \$31.9 billion for the care of people with Alzheimer's disease in the year 2000. Without a cure, the number of Alzheimer's patients will more than triple in the next 50 years. Fourteen million Americans will suffer from Alzheimer's by 2050. If science can help delay the onset of Alzheimer's by even 5 years, it would improve the lives of millions of families and save billions of dollars.

Now I'm fighting to make sure Alzheimer's families have the support they need, both in the lab and in the community. I have introduced legislation that helps to meet the day-to-day needs of seniors and the long-range needs of our Nation. This bill reauthorizes the Alzheimer's Demonstration Program that helps patients and families get support services like respite care and home health care. It connects public and private resources to improve the care for patients and their families. And, it focuses on helping the people who are hardest to reach or underserved. This important program is set to expire this year. I'm fighting instead to expand this program to every State, to keep our promises to America's families. I look forward to hearing from Cass Naugle today about the Demonstration Program in Maryland and others like it around the country.

My bill also addresses the long term needs of our aging Nation by expanding Alzheimer's research at the National Institute on Aging. It expands the Alzheimer's Disease Prevention Initiative to speed up the discovery of new ways to prevent the disease. My bill establishes a research program on ways to help caregivers of Alzheimer's patients.

I fight hard for more funding for Alzheimer's research and care because I understand what Alzheimer's does to those who have it and their families. My dear father suffered from Alzheimer's. We had hoped it was a vitamin deficiency, and all he needed was for the family to pitch in and send Mom and Dad on a cruise. Instead the diagnosis was Alzheimer's. My family and I watched him die one brain cell at a time. My Dad got care right here at Mason Lord. He had a geriatric evaluation and went to adult daycare. I believe that "Honor Thy Father and Mother" is not only a good commandment to live by, it's a good policy to govern by.

Thank you all for coming to today's hearing on Alzheimer's Disease, especially those of you who took time off from work or away from your loved ones to be here. I hope that by coming to you we've made this a little easier. We have two panels today to discuss where we need to go in terms of research and care: Peter Savage, who cares for his wife, Ina, and Cass Naugle, Executive Director of Central Maryland Alzheimer's Association, will testify on the first panel. Dr. Judy Salerno, Deputy Director of NIA, and Dr. Constantine Lyketsos, a researcher at Johns Hopkins University, will testify on the second panel.

Thank you for your great work and commitment to this fight. I am looking forward to our discussion.

Senator MIKULSKI. Before we begin I have a statement of Senator Hutchinson.

[The prepared statement of Senator Hutchinson follows:]

PREPARED STATEMENT OF SENATOR HUTCHINSON

Senator Mikulski, thank you for holding this hearing today. As an original co-sponsor of S. 2059, the Alzheimer's Disease Research, Prevention and Care Act of 2002, I want to express my strong support for your efforts, Madame Chairman, to promote Alzheimer's research and awareness. Alzheimer's is a degenerative neurological disorder that is the leading cause of dementia, which results in impaired thinking, memory, and behavior. It currently afflicts nearly 4 million Americans, a number which is estimated to increase to approximately 14 million Americans by 2050 unless science finds a cure or a way to prevent the disease.

The cause of Alzheimer's disease is currently unknown, and the medications available only slow the progress of the disease. Seventy percent of Alzheimer's patients are cared for at home by family or friends. Their home care will cost an average of \$12,500 per year. Many of these patients need to live in assisted living or long-term care facilities, however. Nursing care for these patients can often exceed \$40,000 per year. The total cost of Alzheimer's care in the United States today is estimated at almost \$100 billion annually. With the aging baby boomer generation approaching retirement, millions of Americans will continue to be affected by this horrible disease. The need for a cure has never been greater.

To help scientists and medical researchers find a cure, I joined Senator Mikulski in supporting S. 2059, the Alzheimer's Disease Research, Prevention, and Care Act of 2002. This important legislation recognizes that the most effective way to curb the number of patients affected by Alzheimer's disease is to find a way to prevent it before it starts. The bill authorizes the Alzheimer's Disease Prevention Initiative, which directs the National Institute on Aging (NIA) to focus its efforts on identifying possible preventive interventions and undertaking clinical trials to test their effectiveness.

In addition, S. 2059 will reauthorize the Alzheimer's Demonstration Grant Program to develop and replicate innovative ways to provide care to Alzheimer's patients that are traditionally hard to reach or underserved. It expands the program by providing funding to support programs in every State. The Alzheimer's Disease Research, Prevention and Care Act also authorizes \$1.5 billion for the NIA for research and development, as well as establishing a program to conduct caregiver research.

Making the investment to treat Alzheimer's disease today means healthier lives for everyone tomorrow. We will find a treatment for Alzheimer's, but first we must make the commitment to invest the resources now to prevent this disease from continuing its progression undeterred.

Senator MIKULSKI. I believe that the best ideas come from the people, so we are going to have two panels today. Our first panel includes Mr. Peter Savage, an old friend and someone I have known over the years who comes with great first-hand experience; and also, Cass Naugle, who is Executive Director of the Central

Maryland Chapter of the Alzheimer's Association. Following that, we will hear from the researchers on our second panel.

Mr. Savage, we welcome you here and look forward to your testimony. I know that you have first-hand insights that you would like to share with us.

Ms. Naugle, I know that you have overseen the growth of the Central Maryland Chapter of the Alzheimer's Association. When you took over, they had a budget of \$50,000; it is now \$1.4 million. I thought I was doing well doubling the NIA budget; I have got to talk to you. You have a lot of secrets to tell me. But I know that in addition to being an advocate, you look out for your mom, who is also dealing with this issue, and you know the pain first-hand.

Mr. Savage, please go ahead.

STATEMENT OF PETER V. SAVAGE, CAREGIVER, BALTIMORE, MD

Mr. SAVAGE. Thank you.

On behalf of three daughters who are at risk, Senator, I would like to thank you very much for your efforts, because I have the problem directly, but I also have the fear of the problem indirectly, and that funding, it seems to me, is going to make a difference. I was asked to talk about the effects of Alzheimer's on family and access to research, which I will try to do.

It seems to me that there are really no generalizations, because each family's situation is slightly different. The progress of the disease manifests itself at different speeds, and where the disease goes quickly, it overcomes emotional defenses and financial resources and, I would imagine, leaves chaos. That has not been my case.

My wife, being Brazilian, and our family approach being an extended family support system, our approach has been—you talk about sweat equity—a lot of family and extended family and a lot of friends who are involved. Each daughter has been a part of research on what has been done. One looked into elder care; one looked at eldercare lawyers; another looked into Alzheimer's support groups, which is how we got to meet Cass. And when full-time support was necessary, they finally placed an ad in the newspaper, and after many mistakes, we found that not necessarily nurses were appropriate, but people who were really resourceful were appropriate. We went through 35 interviewees and finally found a group of people who could serve as a support group for my wife on an around-the-clock basis.

And I would emphasize that perhaps the most important thing in the success of that effort was the compatibility of those people with my wife. My wife does not tolerate fools gladly, and there are a lot of people in this business who will tell you, "I do not do windows, and I do not do this, and I do not do that"—and that is not helpful. What you really need is somebody who can take on the responsibility of dealing with someone who has a flexible agenda and a menu of things that are needed.

Part of the problem in the case of my wife was that she was such a super-confident person to begin with. She still speaks two or three languages, but she spoke five languages. She ran a very tight ship when she ran the household. She brought up three very sane

children, and for better or for worse, she is one of those 30 percent of the people who knows full well what is going on and exactly what are the consequences of where we are going. That produces tears occasionally.

There are still some outstanding issues which we have to face. We have not dealt with all of them. We still have to deal with long-term health care or home care, and there is the possibility of institutionalization, and then the question of how the resources will go to pay for that; and there is increasing dependency.

I would say that in this struggle, there have been some heroes and some villains in the process. I can say that a competent eldercare lawyer—he or she—is clearly one of those heroes. And I will not name names, but I can just say that there are a number of people who are highly recommended. And indeed, I came through Cass Naugle and through Alzheimer's Association and through the recommendations of support groups to find exactly the person or people whom we needed.

I would say that one hero is Dr. Claudia Kawas, formerly of the Johns Hopkins Bayview Neurological Center. Those at Shepherd Pratt who determined that my wife had Alzheimer's in 1995 sent us to her as one of the alternatives, and when she was conducting clinical trials, she slotted Ina for the appropriate place and was very helpful.

She also believed in psychological counseling, saying that it was not a dead-end disease where you just throw people out once they get this disease. So we then worked out with Dr. Koliatsos of Shepherd Pratt and their neuropsychiatric program so that Ina has care and attention, and that is a really good settling influence. It means that you see a psychologist, or you see a social worker, and you have rules of discussion so that when you have problems in the household, you have somebody to go to who is really an arbiter, and that has been no end of help.

I would also say that there are some villains in this fight, and one of the villains is the insurance companies who deny coverage by reason of pre-existing conditions. That is a problem that we have overcome by incorporating; we had to do that to get around that problem. But even so, for example, the Johns Hopkins neuropsychology service cannot accept our insurance because the costs just are not covered, so that something is automatically eliminated.

I would also say that the worst villain is Social Security. They play by their own rules. They do not accept the power-of-attorney. They do not accept a signature stamp. They clearly have a policy of lack of helpful cooperation from the start, and they deny applications just readily. In my case, there is a complicated issue which I am going to have to hire a lawyer to solve.

Remedies—I cannot say that there is any easy one, but get a sense of humor; talk through the problems, including the patient in the discussions. We are now writing a book of 101 bad Alzheimer's jokes. It starts with Easter: One of the benefits of Alzheimer's is that a patient can hide her own Easter eggs.

Thank you very much.

[The prepared statement of Mr. Savage may be found in additional material.]

Senator MIKULSKI. Thank you very much, Mr. Savage. You have raised some very important issues, one of which is the whole issue of medical care and even how, while we are talking about health insurance, the HMO situation, and so on, there is also even a question of what Medicare would pay for.

The Bush administration has made changes which I found out by reading the newspaper. After you conclude your testimony and before we go to the research panel, I am going to ask Ms. Richards on my staff to share with you what we know about what the changes are, because I think we have got to be able to get this out to the community.

Thank you very much for your testimony, and I want to acknowledge your wife being here and the great dignity with which she presents herself.

Mr. SAVAGE. Thank you.

Senator MIKULSKI. Cass Naugle.

**STATEMENT OF CASS NAUGLE, EXECUTIVE DIRECTOR,
CENTRAL MARYLAND CHAPTER, ALZHEIMER'S ASSOCIATION**

Ms. NAUGLE. Senator Mikulski, I am pleased to have the opportunity to discuss the impact of the Alzheimer's Disease Demonstration Grants to States Program. This program was created in recognition that 4 million Americans are affected by Alzheimer's disease and that most of their care is provided in the community by family members.

The goals of the Alzheimer's Disease Demonstration Grants to States Program are to increase the availability of supportive services for people with Alzheimer's and their caregivers and to assure that these services are effectively coordinated.

In addition to working as executive director of an Alzheimer's Association chapter, I have experienced this disease first-hand. First, my father's sister, who helped raise me, developed Alzheimer's, then, my mother's younger brother. My father was then diagnosed, and we cared for him at home for 3 years until he passed away last June. Now my mom is a victim of this disease.

Using adult day services and in-home caregivers, my siblings and I are able to keep her in her home, which is very important to her right now. This is the home where she was born, where she raised eight children, and where she lived with my father for 62 years.

As difficult as it has been to lose people I love to this disease, I know that my family was fortunate. I knew what questions to ask about our family members' care, and I knew where to go for answers to their care needs.

Unfortunately, too often, this is not the case. Finding the way through a complex system of community services can be frustrating to families who are already overwhelmed by the challenges of caregiving.

In working with families at the Alzheimer's Association, the saddest thing I have ever heard from a caregiver is: "I wish I had known about these services when my family member was still alive."

The Alzheimer's Disease Demonstration Grants to States Program helps States to assure that community services are accessible and appropriate for the unique needs of people with Alzheimer's

and their families. The initial program from 1992 to 2000 was created to address the needs of underserved families and gaps in community services. Twenty-nine States received funding through this program.

With this funding, States were able to develop outreach and other services for underserved families in rural and urban areas and also diverse ethnic populations. The program also funded the development of a wealth of training materials for primary and long-term care providers of people with Alzheimer's.

There is a current phase of the Alzheimer's grant program that has funded nine additional States, and the goal of this program is to integrate the dementia services that were developed into the mainstream home and community-based care system.

Maryland has benefitted from this funding in both of the programs, and it has really made a difference for families coping with Alzheimer's. It enabled the four Alzheimer's Association chapters in Maryland to reach thousands of families who were not using services because they did not know they were available, or they did not know how to access them.

The Western Maryland, Eastern Shore, and Southern Maryland sites targeted families in rural areas. These sites collaborate with other community agencies and help to connect families to services.

Here in Baltimore City, we focused on outreach to African American families. This funding helped our chapter to establish three support groups targeted to African American caregivers, and it has resulted in increased participation of African American families in our services.

The Maryland Alzheimer's demonstration grant has had a significant impact on the availability of services for caregiving families, and it essentially built the capacity of the Alzheimer's Association chapters to serve more people more effectively. It enabled the chapters to offer respite care subsidies to give families time off from caregiving. It increased the number of caregiver education programs to inform caregivers about the disease and how to access community resources. It provided for training of assisted living, nursing facility, home health agency and adult daycare staff to enhance the quality of care for people with Alzheimer's. It also helped the chapters train physicians and health care professionals in community clinics to encourage early diagnosis and intervention with treatments and services. Finally, it promoted collaboration among Alzheimer's Association chapters and public agencies to better coordinate care throughout Maryland.

The Alzheimer's Association is currently participating in the Alzheimer's grant program through the Maryland Department of Aging, and Secretary Ward is here with us today. This program has two sites in the State in areas with limited caregiver services—the Eastern Shore and Southern Maryland. The funding has established a consumer-directed respite program for family caregivers. It is also strengthening the skills of health care providers through dementia training, and it is encouraging the development of new services by offering training to entrepreneurs on how to start and manage respite care services.

Senator Mikulski, speaking on behalf of the Alzheimer's Association and the 85,000 Marylanders with Alzheimer's and their fami-

lies, I applaud your efforts to expand these programs through the Alzheimer's Disease Research and Caregiver Act. This bill will help to continue to ensure that no family faces this illness alone by providing essential accessible services and hope for the future.

Thank you.

[The prepared statement of Ms. Naugle may be found in additional material.]

Senator MIKULSKI. Thank you very much for your testimony and for your advocacy.

I am going to talk about the Alzheimer's Association in a minute, but I want to acknowledge that Sue Ward is here. Sue is the head of the Maryland Department of Aging, and all of us who have been involved in issues and services on aging really think she has been doing an outstanding job.

Sue Vaeth runs the Alzheimer's Demonstration Program in Maryland, and she has submitted testimony for the record.

[The prepared statement of Ms. Vaeth may be found in additional material.]

Senator MIKULSKI. Sue Ward, I am not trying to put you on the spot, but as administrator of the program and the one who is handling so many of the information and referral calls, did you want to say anything or add anything?

Ms. WARD. I believe that Ms. Naugle has said it all. The demonstration grant is very exciting for all of us, and we are all very pleased to be a part of it and certainly thank you on behalf of a variety of organizations.

Senator MIKULSKI. Sue, I am going to ask you to join the witnesses at the table for when I ask the questions about the family—and again, I am not trying to put you on the spot—and you know I cannot put you on the spot. But when we speak of Alzheimer's as a disease, it does not exist in the vapors; it exists in the person, and it exists in the family and in the community. So when we are looking at the issues, again we are going to come to the research on treatment, but one of the biggest issues is those who have it now. Alzheimer's affects first the person who has it, the family who cares for the person who has it—it can be a spouse, it can be a parent—and it also affects the community.

When we find the cure—and I believe that one day, we will—we will be able to reduce nursing home admissions and significantly reduce the costs to both families and the taxpayers.

So I am going to focus now on the family issues, and the reason, Sue, that I asked you to come up is because you administer the Department of Aging, and one of the big issues is information and referral as well as caregiving.

Mr. Savage, let me turn to you for a moment. You talked about Social Security being “the villain.” Could you elaborate on, first of all, the ability to find a caregiver and compatibility with your wife? These are all really very difficult issues, but Social Security should be an easy process for you. It is one thing that we should have literally in control—when so many things with Alzheimer's are out of our control.

Mr. SAVAGE. Well, it starts with you have to take a number, and you have to wait in line, and the person with Alzheimer's has to be there, because if anything has to be signed or approved, my wife

has to be there to sign an "X" so that somebody can witness it; she cannot use a stamp.

Senator MIKULSKI. Why were you turning to Social Security? Was it to apply for Social Security?

Mr. SAVAGE. It was to apply for disability, and the question was whether she had enough quarters to qualify for disability. And that has become a very contentious issue which is going to have to go through an appeal for which I will have to hire a lawyer to solve the problem.

I do not know how much you want to hear about this.

Senator MIKULSKI. Well, actually, I will want to hear more about it in a more private setting, respecting your family—but what I find troubling is not only the waiting time—that is a management issue—but let us go to the ability to sign papers, apply, et cetera. I have a power-of-attorney, I have a medical power-of-attorney; you try to plan and do the right thing.

Mr. SAVAGE. They do not accept that.

Senator MIKULSKI. Do you have the power-of-attorney for your wife?

Mr. SAVAGE. I have power-of-attorney which was issued to me, and I had to bring my wife to sign everything and approve everything because they would not accept it.

Senator MIKULSKI. This is really very troubling. In my family, my mother was the executor of my father's affairs, and I was kind of the administrative executive assistant to back them up. My father was already on Social Security, so we did not have to grapple with this. But this is a very troubling issue that you have raised.

So your wife had to sign even though—

Mr. SAVAGE. She had to sign an "X"; she could not use a stamp which we have. She cannot use that.

Senator MIKULSKI. She cannot spell her name?

Mr. SAVAGE. She cannot write in the right slot, or legibly, so we now have a stamp which we had made for her so she can stamp things in somebody's presence—a check or whatever. So the caregiver can go to the store, and she can stamp the check, and everybody knows about it, so it is not unusual. But with Social Security, she has to sign an "X" in the presence of somebody from Social Security, so she has to be there, and it has to be explained to her, and that is complicated, especially after we have had a long wait, and she is getting antsy and impatient and wants to go to the bathroom. It gets to be a complicated issue.

Senator MIKULSKI. I understand, and I find this very, very troubling. I want to assure you right now that first of all, when this hearing concludes, I am going to ask my staff to contact you and, in the appropriate private setting, we want to go over this, one, to see if we cannot help you get it straightened out as a constituent service, and second, if we can, I want to fully understand what you have been through as a case example for me to get into this with Social Security—and I am going to get into it with Social Security.

Mr. SAVAGE. Thank you.

Senator MIKULSKI. You are a man of great experience, you are a well-educated man, you have financial resources, and you are a paperwork guy so you know how to organize yourself. I would say that 65 percent of the American people do not even know about

power-of-attorney and many of these other things. So we want to help you and then, in helping you, in helping the one, we want to be able to help the many.

Mr. SAVAGE. I think the many are very important. And it is not that they were uncivil to me. They were usually civil, but they are not too quick in some cases. Just being able to pull things up on a screen—they could pull it up one time, but they could not pull it up the next time—so just getting to the records and giving you the information that you need to defend your own position was impossible.

Senator MIKULSKI. But you know, the best advocate for the person is the family, and if the family has established the legal right to speak for the individual, you should be able to act on your wife's behalf to be able to do the appropriate things to get her the things to which she is entitled. That is where I am coming in, and I will come back to you.

Cass, tell me about the Alzheimer's Association. Tell me what the Alzheimer's Association does. I think I know, but I would like to hear from you. And then, as executive director, what do people come to you the most about?

Ms. NAUGLE. The Alzheimer's Association was created to fill in the information gaps and service gaps that families had. Back in 1980, families were essentially on their own; they had their doctor, but often they did not know very much about the illness; and they had nursing homes. Between that, the family took care of the care of the person without really too much support.

So the Alzheimer's Association provides a help line that gives families information about the illness, about access to community resources, or anything that they need like support or anything over the phone. We provide respite care, because many of the services that people with Alzheimer's need are not covered by insurance or Medicare.

We have a program called the Safe Return program, because many people with Alzheimer's can wander and become lost.

Senator MIKULSKI. Yes, we have been a supporter of that program with you.

Ms. NAUGLE. Yes. So we provide this program. We provide a lot of caregiver education and training to health professionals who provide care and also, of course, support groups throughout the whole State. Some are for people in the early stages, which is how Peter and Ina got involved with the Association. We have support groups just for spouses; we even have a group for Catholic nuns.

Senator MIKULSKI. And those are Catholic nuns who volunteer to do research, the famous brain study.

Ms. NAUGLE. Yes. So when people call the Association, it is for any variety of reasons. Usually it is, "My family member is starting to act funny; what do I do about that?" And then, after they get the diagnosis, it is, "Where do I go from here?" and we connect the families to services.

Senator MIKULSKI. Where do you send them for diagnosis?

Ms. NAUGLE. We have a listing of health care facilities that we know do a good workup and have a good understanding.

Senator MIKULSKI. And they have an excellent geriatric evaluation program here.

Do you also use the Veterans Administration for older males, usually World War II veterans, and so on?

Ms. NAUGLE. Yes. We have a wonderful connection with the Dementia Clinic that they offer at the VA in Baltimore.

Senator MIKULSKI. After you explain the services—first of all, you do a good job, and I will come to Sue on that—what is the biggest surprise for families and that often adds to their sorrow—because this disease produces grief. As one loses cognitive ability, there is also the loss of the relationship, the loss of income. There is a lot of grief in this; am I correct?

Ms. NAUGLE. Absolutely.

Senator MIKULSKI. So there is the sorrow factor and, in the caregivers, even depression. But from the standpoint of public policy or public resources, what is often their biggest shock and biggest disappointment?

Ms. NAUGLE. Their biggest surprise is that Medicare does not cover the services that they need, or they may have had a high option Blue Cross and Blue Shield for their whole life, but they find that that does not cover adult daycare or someone to help them in the home.

So when families realize that most of those expenses are out-of-pocket, that is a big shock to them.

Senator MIKULSKI. So issues like adult daycare, long-term care and even nursing home care; the big shock is that Medicare is not going to pay for it and that they will have to pay for it, as well as what we would call housekeeping services in the home to help—the kind of folks that Mr. Savage was talking about.

Mr. SAVAGE. It is even a tax deductibility issue. They are very strict as to what you can and cannot deduct; you have to be careful and look at the code pretty carefully. It is a real question.

Senator MIKULSKI. Sue, as you run the Department of Aging, and you try to create a caregiver program and an information referral program, what are people coming to you for? When I say “you,” I mean the Department of Aging and those that are in every county in the State. People do not realize that the Department of Aging is really the primary source of funds, along with local government, of the senior centers, which is usually the gateway for many people.

Ms. WARD. Thank you, Senator, for inviting me to participate. We have submitted written testimony.

Primarily, I think people come in order to get information about resources. As you know, 80 percent or more of the care that is provided to frail older people in the country is provided by the family, and most people can function, as Mr. Savage has, if they know where to go and what to do and receive some help.

In my own family case, I have a grandmother, an aunt and a mother all of whom were demented. She was not eligible for Social Security at all, but it was the reverse mortgage that was my surprise, just for your information, because she could not apply and we had wanted to get a reverse mortgage to provide her care in her home as long as we could.

Back to the question that you asked me, yes, they come primarily for information about resources. Obviously, the Alzheimer’s Association is the primary resource for all of us to use—

Senator MIKULSKI. Do you contract with them?

Ms. WARD. Yes, and in fact this latest demonstration grant is a joint venture. I think Cass got the earlier grant, and then we received this grant, and then we contracted with the Alzheimer's Association for part of that, as well as the area agencies. What we are trying to do, as Cass said, is develop more caregivers in rural areas where there are not the resources that people need to develop micro-enterprises to help people who have never necessarily thought of doing this to provide the care in the home as long as possible, and then to provide the respite services that are necessary for the family. And these providers can be family members.

Senator MIKULSKI. In addition to the issue of a work force in the area of caregiving—because you need not only competency, which is skill-based, but the person has to truly be honest and reliable because of the vulnerability of the population—

Mr. SAVAGE. They have to have judgment.

Ms. WARD. Yes.

Senator MIKULSKI [continuing]. Exactly—and also compassion. I mean, this is not like being a cafeteria worker where getting folks through the line is fine; this takes a lot of very tender, loving care, again with a very vulnerable population.

The federal government provides you with money for information and referral. Is the federal government doing enough to help you help the others?

Ms. WARD. We would obviously like more staff in information and assistance, which is what we call it, because in addition to providing information, we try to help walk people through the process.

Senator MIKULSKI. And it is very time-consuming.

Ms. WARD. Yes.

Senator MIKULSKI. And very difficult. People tell their stories anecdotally. They do not call and say, "I want to know the resources and the regulatory framework for my spouse" or a parent; they will usually say, "My father is really not himself. Mother is doing the best she can," and then go on with their story. Am I correct?

Ms. WARD. Absolutely. I think "Father is acting funny" is one of the primary explanations that people have for calling.

Senator MIKULSKI. But do you think we have adequate services?

Ms. WARD. Absolutely not—and I think Maryland does very well.

Senator MIKULSKI. Where do you think the big service deficits are—and then I would like Cass and Peter to talk about it. What do you think are the service area deficits?

Ms. WARD. Primarily, I think the amount of service is a problem, but also geographic areas. One reason we are concentrating on the rural areas is because if we think about the work force shortage generally in caregiving, rural areas are severely strapped in having people who are willing and able to do this, who can get the training to do this, and who have even thought of doing it. Many people who might want to start a business think of computers or crafts or something else. Caregiving is not necessarily something they think of, but a lot of these people are very experienced in caregiving. They have been doing this all their lives. And the opportunity to continue to do it and to get a little remuneration for it is extremely important, we feel.

Senator MIKULSKI. I want to switch gears now to the research. Peter, is Ina involved in a clinical trial?

Ms. SAVAGE. No. She is taking one medicine now which she would have to stop to involve herself in some of these tests. But through Dr. Lyketsos and Dr. Kawas and others, every time something has come along, we have tried to involve her.

Senator MIKULSKI. But how did you hear about the clinical trials?

Mr. SAVAGE. Basically, when Ina was diagnosed at Shepherd Pratt, when we were then referred over to Dr. Kawas, he was engaged in several of the studies, so they quickly looked at her to see if she might fall into this one or might fall into that, might fall into the other. I was immediately engaged; I am a baseline study for God knows how many studies at the moment, so that any time something new comes along, including the recent vaccination, we try to get around to gatekeepers and get into a study. So through those contacts, we have been able to know what is going on.

Senator MIKULSKI. What gatekeepers?

Mr. SAVAGE. For example, a company that was doing the vaccinations had 365 people in the total sample, and 25 percent of them were going to be given a placebo. I was trying to just get my wife to be considered for the study.

Senator MIKULSKI. I am going to ask you a tough love question, because you are obviously a real fighter for your wife, and God bless you.

Mr. SAVAGE. Yes.

Senator MIKULSKI. You are a real fighter—and thank you, Mrs. Savage.

Then, I am going to ask about this also when we turn to our scientists. But you want to get anything you can to help her, which therefore means even circumventing the protocol; am I correct?

Mr. SAVAGE. You are absolutely right. What does it hurt?

Senator MIKULSKI. We will come back to the protocol. But what it also brings up is your gateway to new knowledge or new resources and so on was because you got to the right area for geriatric evaluation. And again in my father's case, here at Bayview, there was a complete physical, a complete neurological, and a complete psychological, so we would then know if his medications were wrong and that was affecting his memory, or whatever. That then brought us to the team approach which is one of the signatures of the Mason Lord effort here.

But whether you are in a rural area or not, the whole ability to get there is an issue. But it seems to be that the quality of the information is the trigger; am I right, Ms. Naugle?

Ms. NAUGLE. Absolutely, just getting the information out to families. We try through every way possible, through the telephone, and we have a website where we have research opportunities that families can explore.

Mr. SAVAGE. I would also say that Dr. Kawas was excellent at using my wife as the poster girl for Alzheimer's for a while, because she was at one time quite articulate in a couple of languages, so she has appeared at board meetings where we have been trying to raise funds, and she has appeared in *Baltimore Sun* articles, and she has been in *National Geographic*, and she has been on an hour-

long program in Brazil, where it is really an unknown disease in rural areas, and she appeared on "Good Morning America."

All of that then drew information to us, because people discovered that we had a problem, and therefore, people would ask, "Have you tried this?" and we would go and look at that and then check it with Shepherd Pratt or with the Neurological Center here at Bayview to see if it checked out into anything which was responsible and which we should pursue.

So I used all of those resources. Every time I would take an exam, I would get somebody's telephone number, and if I would hear something, I would call them.

Senator MIKULSKI. God bless you. What really emerges is that, first of all, what is absolutely needed from a public policy perspective—and we are going to go to the research in a few minutes—but first of all, we really need people who are trained in this field. This subcommittee held a hearing last year on the shortage of geriatricians, people who are the primary medical caregivers, if you will, of older people, or who train people as to the adequate diagnosis, and then the ability to pay for that diagnosis.

Then, there is the training of primary care physicians to be able to detect the signs of Alzheimer's to get patients diagnosed—because there could be any reason for symptoms—if you have had recent surgery, and you are on medications, you are going to be bewildered and have a memory loss or a memory deficit, but that is going to come back in a matter of weeks.

Then, there is this issue of what Medicare pays for and Social Security; Medicare is a big factor in a family's lives, because there is a family expectation that Medicare is going to pay for this—am I right—and then information and referral.

Mr. SAVAGE. Yes.

Ms. NAUGLE. Yes.

Senator MIKULSKI. So we have a lot of work to do. When we hold our hearing on caregiving, I would like you to be able to come, because we are going to be talking about the States, and I would like you to be able to come, Sue, to talk about that area.

Ms. WARD. Thank you, Senator.

Senator MIKULSKI. We could spend our whole hearing on the issue of caregiving.

The movie "Iris" for which one of the actors won an Academy Award tells the story of Iris Murdoch, one of the great writers of the 20th century, and a brilliant linguist, who herself moves to Alzheimer's. It is about the devotion of a husband, her own spunkiness and so on, and I think this movie is going to raise awareness.

This is tough to face. The first thing is for families to face it, then to get the help they need, and then to make sure that government is on their side and is not adding to their hardship. And while government is trying to help with services, government has to help with the resources.

We are going to go on to the research, but before we do, is there anything else you would like to sum up for me to take back to my colleagues on what we should think about or what we should do?

Peter.

Mr. SAVAGE. Well, my wife is young and therefore does not qualify for Social Security generally because she is only 60 years old.

So that is a problem for younger people who face this issue, and it is more complicated. It is not just an issue of Social Security; it is an issue of what kind of support is available for somebody who does not fit a usual pattern.

And I must say there are resources, and it is wonderful that there are resources, but some of them are not financial resources—it is your own imagination or somehow getting around the problems—and all of that has a cost. I guess I am blessed in that I can shoulder some of these responsibilities, but it would be nice to have some help.

Senator MIKULSKI. Certainly. Good for you.

Cass.

Ms. NAUGLE. Again, Maryland has benefitted so much from the Federal funding that we have received to expand services, and it would be wonderful to be able to expand that to all the States in the country so there would be the same level of service for someone who lives here but is caring for someone in Minnesota.

Senator MIKULSKI. So essentially take the programs nationwide instead of just demonstration programs—because every State is different; for our colleagues in the West, the geography makes a difference, the culture of the community, et cetera. I think that is excellent, and it is a goal of mine. Again, thank you for what you are doing.

Sue.

Ms. WARD. I think there is one other thing that we have not really considered but came to mind today because of something that Mr. Savage was saying. That is that in addition to the caregiving needs, the descendants of people who have Alzheimer's always have a worry—for me, it is a grandmother, an aunt, and a mother, so my children and I are already preparing for the possibility of my developing dementia as well. But that is something that we do not think of in the policy setting. We provide support groups, but do we really deal with that issue. I would like to see us include, at least in Maryland, something in the caregiving nature for helping that innate fear that descendants may have.

Senator MIKULSKI. That is part of the research, too, on genetic proclivity.

This has been excellent, and I want to say God bless you for your excellent advocacy, whether it is the family, community, or government. We really appreciate it.

Ms. WARD. Thank you, Senator, for your advocacy.

Ms. NAUGLE. Thank you, Senator.

Mr. SAVAGE. Thank you.

Senator MIKULSKI. Let us hear from the “genius club” now and see what they want to tell us. We want research, we want magic solutions, and we want them now.

We have two outstanding scientists with us today. Dr. Judy Salerno is Deputy Director of the National Institute on Aging. We need to recognize that the National Institutes of Health are located in Bethesda, MD, but this is a very unique campus in the sense that the National Institute on Aging is right here at Bayview. It is the lead Federal agency for Alzheimer's, and Dr. Salerno is an experienced researcher and an expert on geriatric care, and will tell us about her work. She has also served at the Department of

Veterans Affairs, and I am the appropriator for the Veterans Administration, so I would even welcome your advice and insights on where we could also be using another Federal agency for breakthroughs.

Dr. Salerno has her M.D. and her master's of science in health policy from Harvard, and we want to welcome her.

Dr. Lyketsos, we also want to welcome you. Dr. Lyketsos is an associate professor of psychiatry at Johns Hopkins and is director of the Johns Hopkins Neuropsychiatry Service and Course Director for an ongoing series of continuing medical education programs on Alzheimer's dementia and care of the aging. He is the Baltimore site director of the Alzheimer's anti-inflammatory patient trial and is a principal investigator in many areas. We have been able to attract such outstanding researchers. And again, you have been a very strong advocate.

Dr. Salerno, I am going to ask you to please present your testimony now.

STATEMENT OF JUDITH A. SALERNO, M.D., DEPUTY DIRECTOR, NATIONAL INSTITUTE ON AGING, NATIONAL INSTITUTES OF HEALTH

Dr. SALERNO. Thank you, Senator, and thank you for inviting me to appear before you today to discuss Alzheimer's disease, an issue of considerable importance to every, single one of us.

As a geriatrician and a physician specializing in the care of older persons, I would like to particularly thank Mr. Savage for sharing his story and reminding us of the human toll of this devastating disease.

I first began as a clinical researcher at the intramural program at NIA in 1988. At that time, we rarely considered prevention or cure of Alzheimer's. A little more than a decade later, prevention and cure are the bywords of our research initiative.

We have been able to identify a number of risk factors, both genetic and possible lifestyle factors, and are on the threshold of using powerful brain imaging techniques to help us improve our ability to diagnose Alzheimer's in its early stages.

But most importantly, we are making significant advances toward effectively treating and hopefully even preventing Alzheimer's disease. NIA is currently supporting 18 clinical trials, seven of which are prevention trials. These trials are testing agents such as estrogen, anti-inflammatory, anti-oxidant agents for their effects on slowing the progress of disease or preventing it altogether.

We have recently initiated several clinical trials that build upon findings that focus on possible links between vascular disease and Alzheimer's. For example, as you mentioned, it has been widely reported that high blood levels of homocysteine, an amino acid commonly found in the blood and already considered a risk factor for cardiovascular disease, is associated with an increased risk of Alzheimer's. This is of great interest since blood homocysteine levels can be reduced by increasing intake of foliate, Vitamins B6 and B12.

So we are supporting a clinical trial at NIH to look at the effects of supplementation on cognition in healthy men and women.

Other studies have indicated that the use of statins, the most commonly used cholesterol-lowering drug, may decrease the risk of developing Alzheimer's as well. A trial testing whether statins can slow the rate of progression in Alzheimer's is being launched this year.

The Alzheimer's patient, we have come to realize—and we heard so eloquently discussed this morning—it is not only the patient with the disease, but the entire family unit. Most Americans with Alzheimer's disease are cared for at home by a relative, a spouse, an adult child, an in-law, or a friend.

In addition to the financial burdens this imposes, caregivers frequently experience significant emotional stress and physical strain and often do not receive the support they deserve. Caregiving, as we know, is a 24-hour-a-day, 7-day-a-week job. NIA has invested in REACH, a large, multi-site clinical trial to examine ways we can strengthen caregivers' ability and capacity to care for their loved ones. It is designed to help show us what works and at what cost.

Another critical component of our research is translating basic science findings into clinical interventions. A very promising strategy has been the development of the vaccine approach to preventing or reversing the formation of amyloid plaques on the brain, amyloid plaques being the characteristic lesion of Alzheimer's disease. Human trials of an Alzheimer's disease vaccine were conducted by the Elan Corporation and not funded by NIH, but were halted earlier this year when a number of patients developed brain inflammation.

Despite this outcome, the science on which the study was based continues to be a foundation for building safer strategies for arresting the progression of Alzheimer's.

We have recently funded studies in conjunction with the Neurologic Institute to better understand the science underlying the vaccine approach. Fifteen years ago, we were in the dark about so many things we now understand about the biology and the genetics of Alzheimer's. Ten years ago, we could not model the disease in animals. But today, as you saw on your tour, we have transgenic mice who have been an invaluable tool for modeling Alzheimer's amyloid plaque development in the brain and for testing new therapies.

Five years ago, prevention of Alzheimer's was a distant view. Now we have seven major clinical trials for prevention of this disease. It is difficult to know with certainty how the Alzheimer's story will turn out, but the pace of discovery and the progress we have made in recent years has been breathtaking. Our continued investment in Alzheimer's research will help us sustain the pace and advance our knowledge of safe and effective treatments and prevention strategies that really work.

Thank you, Senator, for this opportunity to appear and report our progress.

[The prepared statement of Dr. Salerno may be found in additional material.]

Senator MIKULSKI. Thank you. We will come back and ask you some questions, but thank you.

Dr. Lyketsos.

STATEMENT OF CONSTANTINE G. LYKETSOS, M.D., PROFESSOR, JOHNS HOPKINS UNIVERSITY SCHOOL OF MEDICINE, BALTIMORE, MD, ON BEHALF OF THE ALZHEIMER'S ASSOCIATION

Dr. LYKETSOS. Senator, good morning. I want to thank you for this very important hearing and for inviting me to testify and also for your staunch advocacy of the Alzheimer's cause.

I also want to acknowledge the Alzheimer's Association and second what you have said about them, as well as the NIA for providing the leadership in the research effort.

I also want to acknowledge several of my staff in the room from our clinical and research team who have taken the time to come today. They are the true workers on the research effort.

I speak to you as a scientist and as a doctor who has taken care of many thousands of Alzheimer's patients, but I also have been touched personally by Alzheimer's in that my wife's grandmother suffered quite horribly from this disease, as I know many others in this room have been affected.

You do make the point that we all support research as critical to the cure and prevention of Alzheimer's. Research is also critical to improving the lives of the 4 million victims currently. I want to remind you, as I am sure you know, that we lead, and the U.S. affects countless others with Alzheimer's around the world who are emulating what we do here, so there is a broader impact of this research.

I strongly endorse the bill that you have submitted, the 2000 Alzheimer's Disease Research, Prevention, and Care Act, and while I am delighted to hear about the \$1 billion increase of NIA funds in general—

Senator MIKULSKI. Now, we reached \$1 billion—we did not add \$1 billion. That is phase two.

Dr. LYKETSOS. I realize that, and that is where I wanted to go—hoping that the \$1 billion in a few years will be dedicated to Alzheimer's research more specifically.

Now, as a Hopkins professor, I want to point out that we are proud to be at the forefront of research and care. Our Memory Disorders Program for the care of patients with Alzheimer's, one of the first ever established in the United States, currently spans all the Hopkins institutions, both here at Bayview, at Hopkins Hospital, and at our affiliate at Copper Ridge. We have developed and provide not only diagnostic evaluations but ongoing care from diagnosis to the end of life for many thousands of people with Alzheimer's. I want to emphasize that already what we do in the care of patients makes a huge difference.

But we are here to discuss research, and research in this area is hard to summarize. In my written testimony, I have gone into greater detail, and I am going to skip ahead to talk a little bit about what I see as the critical issues in treatment research.

The most exciting possibility there that I want to illustrate relates to the possibility of preventing Alzheimer's that Dr. Salerno has already spoken about. This hinges primarily on the recognition that Alzheimer's is damaging the brain for many years—maybe decades—before it actually causes symptoms. An estimate has shown that if we can intervene during that time period, and if we

can reduce or delay the onset of symptoms by 5 years, we would reduce the number of cases by half, which is a substantial impact. Therefore, NIA has initiated this effort.

Our team at Hopkins is involved in three of the seven studies that Dr. Salerno mentioned, and the one that we are furthest ahead with right now and I want to talk a little bit about is the ADAP study, which is the Alzheimer's Disease Anti-Inflammatory Prevention Study. Many of the staff members who are doing the work in this study are in the room.

This study tries to recruit people 70 and older who are healthy seniors who have a first-degree relative with Alzheimer's. We already have at six sites around the country—600 people. We have 120 here in town who are already enrolled in the study, and we have had great help from Secretary Ward and from the Alzheimer's Association in this recruitment effort.

But I want to make the point that we need to eventually get 2,400 participants, and given that we are talking about healthy seniors, one of the major efforts that we are hoping to get help with is the education of seniors about the availability of these research studies and the encouragement for them to participate. It is hard to encourage seniors to participate in these studies. The studies are expensive. I am sure you hear that a lot. It is expensive to do the research. But these sorts of studies take several years, many clinicians, and thousands of participants to give us answers about just a simple drug or two drugs, as we are looking at in ADAP.

In addition to prevention studies, I want to emphasize other treatment studies. Drug discovery in particular, which these days is more of a collaboration between industry and the academic world, needs to be supported because that is ultimately what is going to bring us the cure.

We also need to spend more time on the treatment of the noncognitive symptoms of Alzheimer's. We have shown through our research that as many as 90 percent of people with the disease develop what are sometimes referred to as "psychiatric symptoms," which are very debilitating, including depression, delusions, hallucinations, and the like.

Senator MIKULSKI. Is this prior to the onset?

Dr. LYKETSOS. No. This is after the onset. Through the course of the 10-year illness, 90 percent develop these symptoms. And research into how to treat those symptoms is really in its infancy. We have been doing a lot of it in my group, but I want to emphasize the importance of supporting that research further.

We also do not want to limit ourselves to medication therapies. We are very interested in our group in non-medication treatments for the patients as well as for the caregivers. Just to give you a few examples, we are working now with an exercise intervention to see if, through somewhat aggressive exercise treatment, we can reduce the progression of Alzheimer's disease. That study is funded by the Alzheimer's Association.

We are also developing and researching a distance learning educational program to see whether we can train personal care workers through a CD-ROM interactive program in how to take care of people with Alzheimer's.

So research in those areas will hopefully improve the ability of people to give care day-to-day.

Finally, there is the issue of delivering treatments where they need to be given. You have mentioned this morning the nursing home environment. We know that perhaps as many as 50 or 60 percent of people in nursing homes have Alzheimer's, but we also have not known as much about the assisted living environment. My group is doing the Maryland Assisted Living Study funded by NIMH, the National Institute of Mental Health, and in our first early findings, we are discovering that as many as two-thirds of assisted living residents might suffer from Alzheimer's and that they are not receiving the sort of care that we would want them to receive. So improving the ability to deliver these treatments that already exist and the new ones that come out in these environments where millions of people with Alzheimer's live is an important mission.

I want to summarize by expressing my deep appreciation for your inviting me to speak. We do know that this disease affects all of us personally, and there is a whole range of treatment and other research that is eventually going to need \$1 billion a year hopefully to bring it forward.

Thank you.

[The prepared statement of Dr. Lyketsos may be found in additional material.]

Senator MIKULSKI. Thank you very much for that outstanding testimony, but most of all for the work and the devotion that each of you have spoken with. Obviously, you are deeply involved in thinking about the lives of people with Alzheimer's, their activities of daily living, and their interactions with the people whom they love and who love them and, again, this great loss.

You have been kind enough to mention the bill that I have introduced with Senator Kennedy and others. I was concerned that there needed to be a real focus on Alzheimer's research in the authorizing. Our colleagues on the Appropriation Committee which actually puts money in the federal checkbook are very good, but we developed this legislation called the Alzheimer's Disease Research, Prevention and Care Act. It focuses on prevention and authorizes research on caregiving, which is an area that is often not focused on, plus it is hard to measure, hard to evaluate, and so on, as well as keeping those demonstration projects going. And we do authorize the National Institute on Aging at \$1.5 billion, so I anticipated what you would be asking.

Let me now go to my questions. First of all, you acknowledged the people in the room who are your researchers. I think we should ask them to stand up and give them a round of applause.

[Applause.]

Senator MIKULSKI. We are glad to see all of you.

Cass, do you have people with you from the Alzheimer's Association, the families and the advocates?

Ms. NAUGLE. Yes.

Senator MIKULSKI. Let us give them a round of applause as well.

[Applause.]

Senator MIKULSKI. Very good, very good. This is very dynamic.

I want to ask some questions now. When we talk about prevention, Dr. Salerno—and seven of the clinical trials are here—not only what advice would you give to us in terms of funding the research, but what advice would you give families now in terms of just general prevention? Do you think it is diet, exercise?

Dr. SALERNO. I think we are on the threshold of understanding those issues, but as far as practical information, as we talked about before, increasing foliate in your diet certainly does not hurt, and exercise leading to understanding and prevention of associated diseases like hypertension and diabetes. We have a lot of information about that, and the interplay of those factors is something that we are just beginning to understand.

Senator MIKULSKI. Let me ask about that, because it goes to something that Mr. Savage identified, which is how do you get the medical treatment for someone who has Alzheimer's. We think of someone who might be 72 years old, and they have Alzheimer's and diabetes and are insulin-dependent—no neuropathy signs, but they have to take insulin—this is a difficult patient management issue, first of all in terms of just remembering to take your insulin, to keep track, to do the blood work and so on. Where do people turn, and what kind of research is actually going on to be able to deal with these issues?

Dr. LYKETSOS. I think you have hit upon a critical point. The Alzheimer's patient rarely has just Alzheimer's, and it might be diabetes, it might be heart disease or hypertension; on average, there are two or three other conditions for the typical patient.

Here in Baltimore, where I am fairly familiar with the scene, the groups such as ours at Hopkins Bayview that specialize in this area are overwhelmed by referrals because there is very little training and availability elsewhere.

Senator MIKULSKI. Who is referring?

Dr. LYKETSOS. Lots of sources—the Alzheimer's Association; the families hear about us from word-of-mouth; the NIA; our colleagues in primary care with whom we have worked over the years. We are typically backed up several months because we do not have the staff to handle the kind of need that is out there. We have been trying to grow the programs very slowly around town, but there are not many clinicians who are interested in going into this area. It does not pay as much; it is hard work; there is a lot of after-hours work, and it is frankly very difficult to take care of people with terminal illnesses who are declining for many years.

Senator MIKULSKI. You bring up some very important points. Number one, I am just appalled at the really skimpy reimbursement to primary care physicians taking Medicare patients—just Medicare patients. When you add to that the complexity—first of all, the older you are, you usually have more things that you are coping with, you have more drugs that you are dealing with, and these are important tools for survival. Yet that physician out there, whether it is in Highlandtown or Locust Point or Timonium or Bel Air or Bethesda or wherever, is listening to the patient—first of all, you have to really listen—and then, you are managing multiple diseases and multiple drugs. If you then add a memory loss issue, and if that person does not have a competent caregiver, that even compounds it.

So I think one of our issues is that you cannot be an expert everywhere. There are just not enough of you. Just like there are not enough geriatricians to do this—but the teaching of those involved in internal medicine who, demographically have large populations of the elderly—I think we need to reimburse them so they will have the time to listen and practice the medicine they want to do. Then you all essentially train the physicians so they can do broader-based care.

Is that really a very important public policy?

Dr. LYKETSOS. I think it is. I would want to follow up and go back to something you said earlier, that it is really a team that we need to reimburse. There is a physician, but there is often a nurse, a social worker, an occupational therapist—many times, there is a broader team.

Senator MIKULSKI. Or a nutritionist.

Dr. LYKETSOS. Or a nutritionist. It is a team care approach, and Medicare really limits who it will pay for Alzheimer's-related services.

Senator MIKULSKI. Dr. Salerno.

Dr. SALERNO. I would add that we have to “gerontologize” all of the health professions, that we are never going to have enough people with a specialty in this area, and that we really have to give them the tools to be able to care for a broader range of folks. It really is very much absent in the training of most health professionals, and we need to do more to provide the training and the tools.

Senator MIKULSKI. So that while we are doing research, we really have to put emphasis on training and the training of all—what was the phrase you used?

Dr. SALERNO. “Gerontologize.”

Senator MIKULSKI. Gerontologize. If you can say it, we ought to be able to fund it. [Laughter.] So you are saying across the board in all other training—because somewhere along the line we are all going to get old; that is part of the predictable behavior.

Let me come back to research. Dr. Salerno, what areas of research do you think show the most promise?

Dr. SALERNO. I certainly think that we have shifted into the prevention mode, and I think that understanding the disease and the underlying pathology has given us great opportunities to look for drugs that work, and knowing the mechanisms, we can see where along the line we can intervene, whether it be in the amyloid plaque production and also in nonpharmaceutical approaches, as we heard a few minutes ago.

I think that prevention is really the key now and looking at the disease much earlier than we used to, and that is the progression from a normal, cognitively healthy person to those whom we call mild cognitively impaired to see who will go on to develop Alzheimer's disease—looking at the entire spectrum as we go through that.

Senator MIKULSKI. So early detection—

Dr. SALERNO. Absolutely.

Senator MIKULSKI [continuing]. Which really comes from early observation, it goes to making gerontology part of the basic train-

ing, if you will, of internal medicine and so on, where they begin to see the early signs.

Dr. SALERNO. And then we can intervene earlier and perhaps delay that onset or stop it altogether, and that is really the promise of the research that we are doing now.

Senator MIKULSKI. Let me ask you about complementary medicine. I notice in the seven trials that, in addition to estrogen and so on, you are looking at ginkgo biloba, which you see advertised in every vitamin store that it will help you with your memory.

You need to know that I am a believer in the field of complementary medicine, but I also want to protect my constituents from quackery. That is why I joined with Senator Tom Harkin to establish an Office on Complementary and Alternative Medicine at NIH to be able to do the research.

When people are desperate, they will go anywhere and do anything, from wearing copper bracelets to putting garlic on their earrings. I do not want to trivialize the field, but there are legitimate complementary modalities—and I am glad you are doing this research—as well as those who will exploit the vulnerabilities of people.

First, are you doing research in those areas, and do you have any observations or comments that you would like to make about that?

Dr. SALERNO. Yes. Ginkgo is one of our largest clinical trials to date, and I think it is important that we look at these issues and these interventions in a systematic way so that we can get real answers. I think the potential for harm even in some nutritional therapies that are advocated by the anti-aging folks—and I am anti-aging, but I am certainly—

Senator MIKULSKI. Are you talking about “The Wrinkle Cure” stuff?

Dr. SALERNO. Yes, but certainly we need to do this safely.

Senator MIKULSKI. We all buy the books.

Dr. SALERNO. I visited my mother last weekend in New York, and she has a whole pharmacy on her night table, and I went through and said, “Do not take this, do not take this, take this”—it just shows you that these are our most vulnerable people and people who often do not have a lot of resources to spend on these cures that do not work.

So the research that we are doing is to give us answers and give the public information that we have to get out there when we have the answers, both to health professionals and the public. I think that is very important in getting the message across about what is safe and what is not.

Senator MIKULSKI. Well, two things—first, I agree with you, and I hope there is collaboration going on with the Center for Complementary and Alternative Medicine. Under President Clinton, there was a White House Commission on Complementary and Alternative Medicine, and their report will be coming out, which I think will be very important information that you can use.

Let me go to the non-medication issue. We know we are doing research on those things where there could be a drug for the cure, but most of all, a cognitive stretch-out. As you said, 3 to 5 years can make all the difference financially, emotionally, and so on. But

you have also talked about the non-medication research. Could you elaborate on that for us, Dr. Lyketsos?

Dr. LYKETSOS. Sure. Those of us who have been taking care of patients for many years have realized that there are many strategies that make a difference in their lives and in the lives of caregivers, and the research is now showing that that is not just a difference in quality of life, but it impacts on outcomes like institutionalization. So a team in New York a few years back showed that a very structured education program for the caregiver will delay institutionalization by about a year or two.

There is some other promise that we are hoping to find that exercise interventions in middle stages of the disease, before the motor symptoms happen, would improve the functional course and also delay institutionalization.

Activity interventions might have a lot to do with preventing behavioral problems that occur, agitation that many of the patients experience.

Senator MIKULSKI. What kind of activity?

Dr. LYKETSOS. Basically, structuring the day with something to do, and it probably matters less exactly what you do; it matters more that you do something, rather than leaving the person unoccupied where, in addition to deconditioning their body, they decondition their mind.

So those are the kinds of things that could make a big difference. A point that I often make when I lecture is that the evidence is there already that those interventions in terms of bang for buck have as much success as some of the approved medicines that we have on the market in terms of delaying, say, institutionalization, helping life quality. If we put the two together, it can only improve the mix.

Senator MIKULSKI. What is interesting to me, in addition to looking for the medications, is looking for the genetic therapies for those who might have a family history. They are so promising now that we have new ways of measuring the brain, new ways of developing the protocols, and these mice that help us to learn things faster. Essentially what both of you are saying is that the things that would keep anyone healthy are those things that can be helpful—a diet that is low in fat, big on vegetables and fruits. When in doubt, eat something green, and if you are still in doubt, eat something greener, because that provides the folic acid. All those things that our mothers told us—eat your spinach, eat your kale, pizza is not a vegetable—as well as exercise are important. It would then seem to me that as you are working on this, if people looked at other associations like heart disease, diabetes—the associations are all recommending the same things.

This also goes to education. If I may say, every doctor you go to for just about anything you have will tell you that you need a reasonable diet, and you need to exercise, and they usually have nothing else to tell you after that. So, how do you do exercise?

My mother, who had diabetic neuropathy, learned exercises to do in her home, and she was faithful in doing that: using her wheelchair, walking back and forth on some plastic that we put down to keep those legs moving, one-pound weights that she could use at home, leg lifts—all those practical tips. You are not going to use

a primary care doctor to do this teaching. This then goes to public education in many ways, because it is different exercise for different groups, some homebound. But again, this could even be part of the structure of the day; am I right?

Dr. LYKETSOS. Absolutely, yes. In fact, I want to point out that Laura Poterwels, who is in the room, with our group is a graduate student in our school of public health and is an exercise physiologist who is developing an Alzheimer's-specific intervention program as part of the research.

We are not sure yet how to do this, how to develop the exercise intervention for the person with Alzheimer's disease, because you have to take into account their memory impairment, the availability of the caregiver to help them, and so forth. So it is a really critical issue.

Senator MIKULSKI. Well, first of all, so much has happened since we came here on that very melancholy day when we knew that our father was changing—that was in 1985, so one can get a sense of the progress; it has been almost 20 years. Then, there was care and compassion, and I know that through the adult daycare program here, the structure that it provided, even though we were faithful at home, was a different type of structure. Mother at times needed a breather from him, and he needed a breather from her. And this was great, but even compared to where we were 3 years ago, looking at behavioral issues, diet, exercise, genetics, pharmaceutical solutions, this multi-pronged approach is really so far advanced. And when you think about what the whole Institute is doing for essentially less than \$1 billion a year, I think the American taxpayer should know that we are really getting value for our public investment. There is strong science here, but it is science with practicality and compassion, and that is really outstanding.

Do you have anything else you would like to tell me, just open-ended, about what we should be doing. You see, this becomes a permanent record of the United States Senate's look at what we should be doing. Do you have anything else that you would like to share with me?

Dr. SALERNO. I would just like to say that any funds that we get for research I can guarantee that we will invest wisely, because there is a lot that we can do, will be doing, and I think we have the long view of research, and that is that we are going to find a cure, and we are going to prevent this disease, and that it may not happen tomorrow, but it will happen.

Dr. LYKETSOS. One point that I want to emphasize again to you, Senator, is the importance of teaching our seniors about research participation. That is probably one of the biggest barriers that we face in the field is all the education we have to do every time with every senior.

I gave the example of the ADAP study, where we ask seniors to come in and take a pill every day that might have an anti-inflammatory in it, and they might have to do this for 5 years. Julie Pedrosa, who is our coordinator and also here today, has groups of seniors 20 at a time where she spends a long time discussing what research is about.

So educating our public that this is the research that needs to happen and encouraging them to consider participation will make a big difference.

Senator MIKULSKI. What are the barriers?

Dr. LYKETSOS. There are many barriers. One is their suspicion about research.

Senator MIKULSKI. They do not want to be guinea pigs.

Dr. LYKETSOS. They do not want to be guinea pigs. And that is particularly true among some of the communities that have been badly affected by research.

Senator MIKULSKI. Yes. The African American community remembers Tuskegee.

Dr. LYKETSOS. Right. So that is one big barrier. Another barrier is the concern about the risks of being in research. If you are talking about treatment research, there are side effects to medicines.

There has been a lot of bad press over the last year or two about research, especially in the Baltimore area, so that does not help a lot.

So there are many barriers, and if we can educate our public amongst the seniors that ultimately, it is going to come down to them being in the studies, that that is how the prevention work will be able to succeed in answering the questions.

Senator MIKULSKI. But you know, Doctor, I get calls in my office from people who are desperate, not only in this field, but cancer patients, patients with advanced diabetes, and very often patients with some form of pediatric cancer. People are desperate to get into the clinical trials. They call me as if it is a political perk rather than coming in—but they come so late, and after everything is exhausted, they look to a clinical trial to be, if you will, their final solution or their final grasp. So I do think there needs to be more education about it.

Now, before I wrap up, I would not be me, in Highlandtown, if I did not do what I used to do when I was a Congresswoman. When I was a city councilwoman, and I would come out to the neighborhoods here, and when I was a Congresswoman, we would always have town hall meetings where you could ask me questions, I could ask you questions back, or if you wanted me to “Give them hell, Barb,” at city hall, whether it was William Donald Schaefer or someone else. President Reagan was always particularly mesmerized by what I told him constituents would say. If there is anybody here who would like to ask me a question or something that you would like me to take back to Washington to tell my Senate colleagues and even the White House.

Yes—and please identify yourself.

Ms. BOSWELL. My name is Tara Boswell, and in addition to working as a facilitator for the Alzheimer’s Association, I work in adult daycare. One of the questions and concerns that I have is that medical assistance does not recognize Alzheimer’s as a legitimate need for medical daycare, and a lot of people are turned away who could really benefit from the structure and socialization that the doctor was talking about. So that was one thing that I was hoping you could take back with you.

Senator MIKULSKI. Very good. That is an excellent point.

Anybody else? Yes?

Ms. WEST. I am a facilitator for the Alzheimer's Association also, and I had a problem with the power-of-attorney for my aunt. The lawyers suggested that my cousin get custody rather than power-of-attorney, and it worked out better for him for that particular reason.

But I would also like to know about people who have to leave their jobs to take care of a person or a family member with Alzheimer's. There seems to be no support out there for them, no medical insurance for them, and that is also a problem.

Senator MIKULSKI. What is the issue—loss of an income?

Ms. WEST. The loss of income, and when they try to get medical assistance for themselves, they are told, "That is your choice; you chose to stay home and take care of that person," when there was no one else there to take care of them.

Senator MIKULSKI. May I ask your name?

Ms. WEST. Shirley West.

Senator MIKULSKI. Ms. West, when we hold our hearing on caregiving, this is one of the issues that we want to bring out. We have been talking about this because again, caregiving is also a tremendous loss of income, or in families where they take a part-time job, it is usually the women who do this.

Second—let us just say it is a daughter helping out a parent. I will use that as an example—it affects her income, it affects her own Social Security in the future, and it also means that if you are part-time, you cannot get health insurance unless you go the individual route, and then it costs you \$6,000 or \$7,000—and if you could afford that health insurance, you would not worry about it in the first place.

Am I on the right track?

Ms. WEST. Exactly.

Senator MIKULSKI. Well, thank you. You bring up a very good point, because we have to find a way to acknowledge particularly those who take a step-down in their own income to be able to help their families.

In another administration, when I was working with Vice President Gore, we were looking at the Social Security issues for both homemakers and caregivers because of their loss of income. It was like a "Mommy tax," and the better the daughter, if you will, she was penalizing herself.

So we want to come back and look at that, and you raise a very good point. Thank you for bringing it to our attention.

Anybody else? Yes?

Ms. SIGURDSON. Senator, my name is Kathy Sigurdson. I am a former caregiver of my husband who had Alzheimer's. To me, it is very important to have support for the caregivers. It is important to have more research funds to find a cure and more support for the caregivers for the Safe Return Program. My husband was lost for 90 minutes. The caregiver support program, the daycare, was very important to me because I could concentrate on work and know that he was safe for 8 hours.

Senator MIKULSKI. I am sorry—what is the thing that is important to you?

Ms. SIGURDSON. The daycare.

Senator MIKULSKI. The adult daycare.

Ms. SIGURDSON. Yes. I was able to go to work knowing that he was safe for 8 hours.

Senator MIKULSKI. And not only safe, but getting the support and encouragement that he needed.

Ms. SIGURDSON. Yes, yes, and the structure that he needed. So the caregiver support program is very important, Safe Return is very important, and money for research—hopefully more than \$1 billion.

Senator MIKULSKI. Thank you for your eloquence. Thank you. Anybody else?

Mr. SAVAGE. Get campaign reform in place and make it work.

Ms. WARD. Senator, there is another barrier that seniors have to participating in research, and that is that they want to know whether they are in the control group or—

Senator MIKULSKI. They want to know if they are on the placebo.

Ms. WARD. Exactly.

Senator MIKULSKI. But then, it is not a placebo if you know you are getting it. The placebo is the belief that you are getting it.

Ms. WARD. Yes, but they do not want to participate if they are not going to get help, and that is another barrier.

Senator MIKULSKI. And that is one of the challenges of research; it really is. But I think we are an informed public, and also, I think there are also generational differences. I think that younger people as they are coming along are more interested. But this is it.

It seems, though, that we have to work on the cures; then, we have to work on those who are part of a team, whether they are social workers, doctors or nurses, to really understand, first of all, the normal processes of aging so you can know what is not going well; and then, as they are able to identify it, to get people on the right track; and then, we really have to pay people. We really have to pay doctors, we have to help the nurses, et cetera. So we have some big challenges.

I want to ask the exercise lady to tell me what you are doing.

Ms. POTERWELS. I am currently working on a Ph.D. in public health at the Hopkins School of Public Health, but Dr. Lyketsos and I are working on exercise trials. This is a small pilot trial where half of the people will get a home-based exercise intervention which involves the resistance bands and personal instruction as well as pictures of each exercise, so that hopefully, they cannot really go wrong, and personal attention. The other half will get a home safety evaluation and recommendations for improving that.

We are hoping to at least improve the functional ability or at least maintain the physical function and activities of daily living of these people.

Senator MIKULSKI. What are you looking at, though? Are you looking at what exercises might improve cognitive ability? Are you looking at how to get older people in an exercise program and have them stick with it?

Ms. POTERWELS. We are actually just recruiting Alzheimer's disease patients, so it is only going to be those who have a caregiver that is with them for at least 10 hours a week; and we will be doing this home-based exercise program and looking at the beginning and at the end for cognitive outcomes, behavioral outcomes,

as well as physical functioning to see if it improves or maintains that.

Senator MIKULSKI. Yes, Dr. Salerno.

Dr. SALERNO. I would just like to add that the NIA has a major campaign for the promotion of exercise among all older people, and we have a free booklet that you can get by going on line, and you can get the telephone number on our website or call our Alzheimer's Disease Education and Referral Center. It tells you how you can safely in later age exercise and keep yourself health.

Senator MIKULSKI. I am a big believer in videos, and I would love to know from all of you if it is included in the funds to get the information out, because sometimes the ability to put out into the public what we have already learned is critical—things that are so practical—we have got to find better ways of doing that.

The great thing about a video is that the caregiver can come in and watch it, but so can the 15-year-old niece or nephew who says, "I am going to do this with Grans or Pops," and turn it into a fun thing, rather than everybody being gripped with sadness or feeling helpless. This is not the grandfather you used to go fishing with, and what can you do? Well, maybe it is playing hoops from your own living room—speaking of the Terps these days.

Dr. SALERNO. We have a video, too.

Senator MIKULSKI. Good. I would like to see that video.

I know my staff is going to start handing me these little blue cards that tell me it is time to wrap it up. But first of all, I want you to know that I have found this conversation very informative and very instructive for all who participated, but I also want you to know that I found it very inspirational. I am really inspired by the dedication of American families to the people they love. You know, we do a lot of analyzing of our society about what is right, and maybe it is not the way it was, but just listening to you, I know there is a tremendous amount of dedication, as well as among the scientists and the clinicians and all of their work. You have really inspired me. You have really energized me. You have really encouraged me to eat more folic acid, to "Go green," and get my own exercise program.

So just know that when I am in Washington, I will never forget you. God bless you.

[Additional material follows.]

ADDITIONAL MATERIAL

PREPARED STATEMENT OF PETER V. SAVAGE

Ina Dutra Savage, born in Rio de Janeiro, Brazil in 1941, came to the U.S. for the first time to attend high school as an international exchange student in 1958. After graduating from Mineola High School, she returned to Brazil to attend the Catholic University of Rio, where she got a degree in sociology and became an associate teacher at the university. Because of her linguistic ability—she spoke Portuguese, French, English and Italian—she was hired by the U.S. Embassy to serve as a social secretary assigned to the U.S. Ambassador, Lincoln Gordon. In this job, she met her husband, Peter Savage, and they were married in 1967. She was assigned with her husband, a CIA officer, to Brazil and, later, Argentina, returning to the U.S. in 1978, with her husband and three daughters. When her children were of school age, Ina enrolled in a Master's Degree program for linguistics at University of Maryland, graduated in 1988 and was licensed to teach French and Spanish in the Baltimore public school system in 1990.

The first sign of any difficulty for Ina was her apparent inability to remember her teaching program in classes and her inability to maintain class discipline—both very much out of character. In 1991, she had to resign as a teacher and signed up as a translator/interpreter for Spanish, French and Portuguese. Other lapses and orientation problems appeared and, in 1993, she was referred to a neurologist. After more than a year of exams, observation, and tests it became apparent that there was a progression to her ailment and she was referred to Shepard Pratt for more analysis. After long study, she was diagnosed with Alzheimer's disease in October, 1995. At that point, the impact on the family began to be felt.

The first problem was that Ina could no longer drive a car, so that getting kids to and from school, shopping, and daily activities were shifted to her husband or older daughters, two of whom were off at college. The Alzheimer's Association was helpful in identifying support groups where others could point the way to the problems we faced. An elder care lawyer had to be identified, our wills and living wills had to be drawn up), and we had to plan for our future finances to deal with an uncertain future with an uncertain timeframe.

IMMEDIATE AND PRESSING PROBLEMS

The immediate concerns following the diagnosis were:

- Where could Ina's husband, Peter, find a job that allowed flexible time for him to deal with the family chores Ina could no longer perform?
- How could we get health insurance that could avoid a pre-existing condition exclusion for the Alzheimer's?
- Where should we go for medical attention to the immediate manifestations of a disease that was, probably, Alzheimer's?
- What resources were available to support any of these decisions that had to be made?

LONG TERM PROBLEMS

Longer term problems also loomed and needed consideration in the short term:

- If institutionalization were the likely end of the line for Ina, how would she qualify for Medicare and Medicaid?
- Social Security had not recognized several years of Ina's independent contractor work and, accordingly, disqualified her time necessary to qualify for benefits. How to deal with this?
- What were the roles that each member of the family would take on as Ina's abilities declined?
- Who are the lawyers, accountants, brokers, psychologists, and support groups who can help sort out these questions?

None of these questions has a definitive answer that suits every family. Certain it is, however, that when a mainstay of a household becomes incapacitated—becomes a vegetable—the world of a family is stood on its head. And if there are insufficient financial resources to meet unexpected needs the impact can be ruinous and relationships within the family unbearable.

While some of these questions remain unresolved, there were answers for the short term—pressing questions. Peter got a real estate license and became a commercial broker so that his hours were flexible and he could tailor work around family demands.

The family became an incorporated entity where all, including Ina, were salaried employees or dependents, so that, under Maryland law, a health insurer could not deny coverage by reason of pre-existing conditions.

Shepard Pratt referred us to Claudia Kawas, a neurologist conducting various tests for new drugs aimed at Alzheimer's disease at the Bayview Neurological Center at Johns Hopkins, who introduced various courses for enrolling in new clinical trials. Staff working with Dr. Kawas were helpful in assessing how our resources should be allocated in meeting the crisis. They recommended a book, "The 36 Hour Day," by Dr. Peter Ravens (and others). This book was indispensable reading.

In addition, Dr. Kawas was in a position to diagnose Ina's situation to see which study might be most suited to her treatment. In the end, however, Ina would have had to discontinue taking drugs which had proven beneficial (donepezil) to qualify her for several of the studies being conducted by Dr. Kawas or for other studies being considered in the field. Ina is presently involved in a long term study measuring the progression of memory disorder at the Bayview Research Center and has donated her brain on her death, to Johns Hopkins.

Her present doctor, Vassilis Koliatsos, of Shepard Pratt Neuropsychiatry Program, has also kept us current on new clinical trials under consideration and advised us on what courses to consider. Ina volunteered for the positron emission tomography (PET) study at Johns Hopkins but, again, she would have had to stop taking donepezil for a 6-month period prior to the study.

Dr. Constantine Lyketsos, of the Johns Hopkins Neuropsychiatry Service was very helpful in getting Ina around the gatekeepers to the ELAN/EN1792 vaccine study at the Mayo Clinic last September, but her mini-mental scores were lower than the candidates permitted in the sample. This test was ended abruptly and her non-participation was probably a grace.

Most of the longer term problems have still to be resolved, but the most aggravating part has been dealing with the bureaucracy at Social Security who have been so unhelpful that a lawyer has had to become involved at considerable expense.

The roles of family members are still being resolved. Ina now requires caretakers 24 hours a day, so the daughters have advertised for caretakers, interviewed them, made a schedule and coordinated it so that Peter can have his work day free to go to the office and have weekend activities out of the house. One daughter acts as a caretaker 3 days a week and Peter is on duty nights and weekends.

The long-term prospects are still clouded by Ina having to qualify for disability and Medicaid within the time that she may require permanent institutionalization. In addition, the family has been challenged by the difficulty in finding appropriate activities to keep Ina stimulated as the disease has progressed. Each case of Alzheimer's disease affects the family and the individual differently. Services and supports that are utilized by one family or individual may not meet the needs of another.

Senator Mikulski, I thank you for inviting me to speak at this hearing and for the opportunity to discuss how Alzheimer's disease has affected the Savage family.

PREPARED STATEMENT OF CASS NAUGLE

Senator Mikulski and honored guests, I am pleased to have the opportunity to discuss the impact of the Alzheimer's Disease Demonstration Grants to States Program. This program was created in recognition that Alzheimer's disease affects 4 million Americans and that most of their care is provided in the community by family members. The goals of the Alzheimer's Disease Demonstration Grants to States Program are to increase the availability of supportive services for people with Alzheimer's and their caregivers, and to assure that these services are effectively coordinated.

In addition to working as executive director of an Alzheimer's Association chapter, I have experienced this disease first-hand. First, my father's sister, who helped raise me, developed Alzheimer's, then my mother's younger brother. My father was also diagnosed. We cared for him at home for 3 years until he passed away last June. Now my mom, my hero, is a victim of this disease. Using adult day services and in-home caregivers, my siblings and I are able to keep her in her home, which is very important to her at this point. This is the home where she was born, where she raised eight children, where she lived with my father for 62 years.

As difficult as it has been to lose people I love to this disease, I know my family was fortunate. I knew what questions to ask about our family members' care and I knew where to go for answers to their care needs. Unfortunately, too often this is not the case. Finding the way through a complex system of community services can be frustrating to families already overwhelmed by the challenges of caregiving.

As executive director, the saddest thing I have ever heard from a caregiver is "I wish I had known about these services when my family member was alive."

The Alzheimer's Disease Demonstration Grants to States Program helps States assure that community services are accessible and appropriate for the unique needs of people with Alzheimer's and their families. The initial program in 1992 was created to address the needs of underserved populations and gaps in community services for people with Alzheimer's. Twenty-nine States received grants through this program. With this funding, States were able to develop outreach programs and educational materials for under-served rural, urban and diverse ethnic populations. It enabled States to develop respite resources and other supportive services. The program also funded the development of a wealth of training materials for primary and long-term care providers of people with Alzheimer's.

The current phase of the Alzheimer's Disease Demonstration Grants funded nine additional States. The focus is on integrating dementia care services into the mainstream home and community based care system.

The four Maryland chapters of the Alzheimer's Association benefited from this critical funding in the first demonstration program from 1992 to 2000 and it has truly made a difference for families coping with Alzheimer's disease. It enabled the Alzheimer's Association to reach thousands of families who were not using services, because they did not know they were available or because they did not know how to access them.

The Western Maryland, Eastern Shore and Southern Maryland sites targeted families in rural areas. These sites collaborated with other community agencies and developed care coordination programs to help effectively connect families to services. Here in Baltimore City, we focused on outreach to African American families. This funding helped our chapter to establish the three support groups targeted to African American caregivers, and it has resulted in increased participation of African American families in all of our services.

The Maryland Alzheimer's Demonstration Grant has had a significant impact on the availability and accessibility of supportive services for caregiving families. It enabled the chapters to offer respite care subsidies, to give family caregivers time off to rest. It increased the number of caregiver education programs, to inform caregivers about the disease and about how to access community resources. It provided for training of assisted living, nursing facility, home health agencies and adult daycare staff, to enhance the quality of care for people with Alzheimer's. It helped the chapters to train physicians and health care professionals in community clinics, to encourage early diagnosis and intervention with treatments and services. Finally, it promoted collaboration among the Alzheimer's Association chapters and public agencies to better coordinate care and services throughout Maryland.

The Alzheimer's Association is participating in the current Alzheimer's Demonstration Grant Program through the Maryland State Department of Aging. This program has sites in two areas of the State with limited caregiver services, the Eastern Shore and Southern Maryland. The funding has established a consumer-directed respite program for family caregivers. It also is helping to strengthen the skills of existing and future health care workers through dementia training. It is encouraging the development of new services by offering training to entrepreneurs on how to start and manage a respite services business.

Senator Mikulski, speaking on behalf of the Alzheimer's Association, and the 85,000 Marylanders with Alzheimer's and their families, I applaud your efforts to expand these critical programs through the Alzheimer's Disease Research and Caregiver Act. This bill will help continue to ensure that no one faces this illness alone, by providing essential, accessible services and hope for the future.

PREPARED STATEMENT OF SUE VAETH

Ms. Chairman and Members of the Committee:

I am pleased to submit written testimony on behalf of the Maryland Department of Aging (MDoA) regarding Maryland's Alzheimer's Demonstration Project.

MDoA's mission, in partnership with the local Area Agencies on Aging, is to provide leadership and advocacy for older Marylanders and their families through information, education, programs, and services that promote and enhance choice, independence and dignity. The Alzheimer's Demonstration Grant Project allows us to develop new methods of providing services that address our mission.

Given the recent increases in State and Federal funding for services in the support of family caregivers, the State needed to build on its current service delivery systems to facilitate the access of families caring for individuals with dementia to the services that were developed with these funds. Maryland began this process by taking advantage of the National Alzheimer's Demonstration Project funding to im-

prove the responsiveness of the existing home and community-based care system for persons with dementia and their families. Maryland's project focuses on developing an innovative rural model that addresses the critical lack of dementia-competent service providers, as well as providing respite to families in the ways families determine to be most helpful. As part of this project, MDoA is working with private partners to move interdepartmental and community-based efforts forward to create a more efficient and accessible system. The Alzheimer's Association and local micro-enterprise business developers play a significant role in this project.

Background

The State of Maryland received Alzheimer's Disease Demonstration Grants to States funding from 1992 to 2000. During this time the Alzheimer's Association chapters, in partnership with the Maryland Department of Human Resources, led successful outreach efforts to inform rural areas and the City of Baltimore about resources for individuals with Alzheimer's disease. The funding helped develop and grow a new Alzheimer's Association chapter on the Eastern Shore, established a branch office in Southern Maryland, and assisted the Western Maryland Chapter to establish a branch office in Hagerstown. The project dramatically improved the capacity of the Central Maryland Chapter to serve African-American families and improve care networks in Baltimore City. The demonstration project made significant progress in developing support groups among minority and rural populations, as well as training family caregivers. In recent years, the project trained hundreds of health care providers and physicians about Alzheimer's disease.

This project was noteworthy in its ability to involve communities in addressing their own particular needs. A strong infrastructure now exists in rural, underserved areas as a result of this demonstration grant.

Since the inception of this project, significant changes have occurred. While Alzheimer's disease is now a household word, families in rural areas are still having difficulty accessing services. Those with and without the ability to pay cannot find individuals who will provide the care needed. The booming economy of the late 1990s and early 2000 created a demand for employees and low unemployment. Individuals willing to accept a demanding, skilled position for low wage, inconsistent hours and few benefits became increasingly more difficult to find, even in rural areas with higher than average unemployment. Developing new services for people with dementia in rural areas is challenging. The lack of large population centers, the absence of a private-pay market, the small or non-existent pool of trained employees, and the inadequate reimbursement from public sources, creates an unresponsive environment for individuals or organizations seeking to serve the growing population of individuals with dementia.

The new Alzheimer's Demonstration Project provides the technical assistance necessary for developing these potential providers' capacity to meet the demands of the growing aging population.

The Demonstration Project

The Maryland Alzheimer's Demonstration Project (ADP) has two objectives: (1) the project will expand the number of rural providers of dementia-competent care through developing micro-enterprises, or small businesses owned by low-income entrepreneurs; and (2) the project will implement a consumer-directed respite care model to improve the responsiveness, efficiency and quality of care for people with dementia and their families.

The project is being piloted by three Area Agencies on Aging (AAA), St. Mary's, Charles, and MAC, Inc., which serves the four lower Eastern Shore counties. All sites focus on the low-income, rural population.

At least sixty individuals and families will receive respite care in a way that provides the most relief to them. Families are given guidance and counseling in developing a plan for services. They determine who will provide the care, and when and how often it will be used. Families may identify neighbors or other family members to provide respite care, or they may choose a provider agency or an adult daycare center.

The individuals with dementia were on a waiting list for Maryland's Senior Care Program services. The Senior Care Program, financed by State funds and administered by MDoA, fills gaps in services for low-income, older people who have significant functional impairments. The Senior Care Program creates a package of services that assists individuals to remain in their homes rather than enter a long-term care facility. The waiting list exists because of limited funding and the lack of service providers. Respite funds from the Alzheimer's Demonstration Grant Program have immediately enabled individuals who qualify to begin to receive services. Most im-

portant, family caregivers are in charge of what kind of respite services will be provided and who provides the services.

The consumer-directed model will be implemented in tandem with activities to address the lack of qualified service providers in rural areas. The Maryland ADP is tackling this issue using a strategically executed effort to assist individuals to become independent contractors, to develop micro-enterprises or small businesses owned and operated by low-income entrepreneurs, and to enhance the dementia-care expertise of existing providers who may not currently serve individuals with dementia.

As a result of Maryland's efforts, we expect that at least twenty-five micro-enterprises will develop business plans and begin service to individuals with Alzheimer's Disease and their families. The micro-enterprise partners will train individuals who express an interest in starting their own caregiving businesses. The new entrepreneurs will attend classes that include tax and regulations issues, and other relevant business practices. In addition, new providers, other existing providers, and family members may receive specific training on working with people who have dementia.

The Maryland Department of Aging will develop a manual on consumer directed services and the Alzheimer's Association will develop a manual for how to create micro-enterprises. The manuals will be published and made available so this project can be duplicated in other Maryland counties and nationwide.

The Maryland ADP will result in an improvement in the families' satisfaction with the services they receive, improved access to respite and other services that assist families to care for individuals with dementia, and improved service delivery systems.

Accomplishments

In the first nine months of the project, the participating Area Agencies on Aging have provided case management and/or respite services to 67 families. The Alzheimer's Association has entered into partnerships with local micro-enterprise businesses to develop a curriculum and training for potential providers. The first of these training sessions is scheduled for April 2002. Thirty-two people have signed up to take these business classes. The Alzheimer's Association has also held several training sessions about dementia for family caregivers and existing care providers. Additional training sessions will be offered throughout the grant period.

The following story illustrates how the demonstration project, with just a little bit of money and some case management guidance has made a difference for one family.

Mary, 29-year-old woman, has been caring for her mother for 6 years. Mary's mother is diagnosed with Alzheimer's disease, and needs 24-hour care due to constant pacing and wandering. Mary's mother cannot attend the adult daycare center because of the wandering. Mary assists her mother with feeding, bathing and other personal care. She does not want to place her mother in a nursing home.

Mary's husband works during the day and takes care of their two children, ages 6 years and 6 months, and his mother-in-law in the evenings. Mary works part time in the evenings at a fast food restaurant in order to help meet financial obligations.

When the case manager first visited her, Mary was tearful, exhausted and afraid of losing control. With the guidance of the case manager over several visits, Mary was able to find a friend who could help her care for her mother. The grant funds pay for this expense. If not for the grant, Mary would not be able to get respite assistance. If she desires, Mary's friend will be able to take advantage of the dementia training that is offered by the Alzheimer's Association.

PREPARED STATEMENT OF JUDITH A. SALERNO, M.D.

Senator Mikulski:

Thank you for inviting me to appear before you today to discuss Alzheimer's disease (AD), an issue of interest and concern to us all. I am Dr. Judith Salerno, Deputy Director of the National Institute on Aging (NIA), the lead Federal agency for Alzheimer's disease research. As a geriatrician who has spent much of my career working with AD patients and their families, I am delighted to be here this morning to tell you about the exciting progress we are making toward understanding, treating, and preventing AD.

As you know, AD is a major public health issue for the United States, and it has a devastating impact on individuals, families, the health care system, and society as a whole. An estimated 4 million Americans are currently battling the disease, with annual costs estimated to exceed \$100 billion. Moreover, the rapid aging of the

American population threatens to increase this burden several-fold in the coming decades.

However, despite the grim statistics, we have made, and are making, tremendous progress.

When I first began working with AD patients as a clinical researcher in NIA's Intramural Program in 1988, preventing or curing AD was considered, at best, a distant possibility.

Our understanding of AD's underlying biology was limited, and for this reason it was difficult even to predict what might be effective as a treatment or preventive.

Today, the picture is considerably brighter. Through laboratory and population-based scientific studies, we have identified a number of risk factors for AD, including both genetic and possible lifestyle factors. Research supported by the NIA and the National Institute of Mental Health (NIMH) has identified several genes that can cause AD, thereby helping us identify pathways affecting its development or progression, which will lead to better molecular predictors of the disease even before it is clinically apparent.

The development and refinement of powerful imaging techniques that target anatomical, molecular, and functional processes in the brain will give us an improved ability to diagnose AD early, while the patient can still take an active role in decisionmaking.

These techniques, along with better neuropsychological tests, are also enabling us to identify people who are at very high risk of one day developing the disease and to determine just how the disease starts in brain. This knowledge, in turn, may allow early intervention in persons long before the disease affects their level of functioning.

Most importantly, we are making significant advances toward effectively treating, or even preventing, AD. NIA is currently supporting 18 AD clinical trials, seven of which are large-scale prevention trials. These trials are testing agents such as estrogen, anti-inflammatory drugs, and anti-oxidants for their effects on slowing progress of the disease, delaying AD's onset, or preventing it altogether. We eagerly await the results of these trials.

As we search for effective preventive interventions and treatments for AD, it is becoming clear that, rather than seeking only a "magic bullet" that will, by itself, prevent or cure the disease, we may be able to identify a number of potential interventions that can be used to reduce risk. Several recent studies have highlighted this.

For example, a recent study in the *New England Journal of Medicine*¹ indicates that elevated blood levels of the amino acid homocysteine, already considered a risk factor for cardiovascular disease, are associated with an increased risk of developing AD. The relationship between AD and homocysteine is of particular interest because blood levels of homocysteine can be reduced, for example, by increasing intake of folic acid (or folate) and vitamins B6 and B12. And, in fact, in a separate study in the *Journal of Neuroscience*,² NIA researchers show that folic acid may protect mice against some of the symptoms of AD. NIA has ongoing clinical trials of these substances to test whether supplementation can slow the rate of decline in cognitively normal men and women as well as in women at increased risk for developing dementia, and a trial on people diagnosed with AD is due to start in 2003. Other studies have indicated that the use of statins, the most common type of cholesterol-lowering drugs, may lower the risk of developing AD. A study of statins to slow the rate of disease progression in AD patients is planned for fall 2002.

Another promising area of study is the role of mentally stimulating activities throughout life as a factor capable of maintaining cognitive health or even reducing the risk of cognitive decline or AD. Through its Advanced Cognitive Training for Independent and Vital Elderly (ACTIVE) study, NIA is currently exploring whether three specific interventions (on memory, reasoning, and speed of processing) can maintain or improve functioning in unimpaired, community-dwelling older adults. In addition, NIA-supported researchers recently found that more frequent participation in activities such as reading, doing crossword puzzles, or playing card games is associated with a reduced risk of later developing AD.³

¹S. Sesdradri, A. Beiser, J. Selhub, et al., "Plasma Homocysteine As A Risk Factor For Dementia and Alzheimer's Disease," *N. Eng. J. Med.*, 346:7, pp.476-483.

²Kruman, T.S. Kumaravel, A. Lohani, W. Pedersen, R.G. Cutler, Y. Kruman, N. Haughey, J. Lee, M. Evans, and M.P. Mattson, "Folic Acid Deficiency and Homocysteine Impair DNA Repair in Hippocampal Neurons and Sensitize Them To Amyloid Toxicity in Experimental Models of Alzheimer's Disease," *Journal of Neuroscience*, 22:5, pp.1752-1762.

³Wilson RS, Mendes de Leon CF, Barnes LL et al., "Participation in Cognitively Stimulating Activities and Risk of Incident Alzheimer Disease," *JAMA* 287: 742-748.

In addition, scientists funded by NIA and NIMH are developing and refining powerful imaging techniques that hold promise of earlier and more accurate diagnosis of AD, as well as improved identification of people who are at risk of developing the disease. For example, recent studies suggest that positron emission tomography (PET) scanning of metabolic changes in the brain and magnetic resonance imaging (MRI) scanning of structural brain changes may be useful tools for predicting future decline associated with AD and other neurodegenerative diseases. Researchers have also developed a new method of functional MRI (fMRI), a technique for visualizing activity of brain structures, that is both easier on the person being tested and capable of imaging smaller structures in the brain than has been possible in the past.

These methodologies may also be useful for evaluating the efficacy of drugs in stemming the progression of AD or preventing its onset altogether. However, these and other emerging imaging techniques, while promising, require further testing and analysis before they can be routinely adopted in the clinical setting.

Another very important area of research involves easing the burden on caregivers of AD patients. In a sense, the AD "patient" is not only the person with the disease, but the entire family unit is. Most Americans with AD are cared for outside the institutional setting by an adult child or in-law, a spouse, another relative, or a friend. The financial costs of this care can be devastating to families; by one estimate, the average lifetime cost per person for patients with AD is \$174,000. In addition to these financial burdens, caregivers frequently experience significant emotional stress and physical strain, yet they often do not receive adequate support.

NIA is investing in new approaches to assist these often forgotten Americans. A first priority is to assess the magnitude of the problem. For example, the ongoing Aging, Demographic, and Memory Study (ADAMS) has been designed to assess dementia and AD among Americans, the burden on caregivers, the economic cost of dementia to families and to society, and the burden of dementia over the course of the illness.

NIA is also supporting a study of a combined behavioral and drug intervention on patients with mild AD. In this study, caregivers will be key participants in the behavioral intervention, and the researchers hypothesize that this participation will reduce caregivers' psychological stress. In addition, NIA is supporting a large, multi-site clinical trial, REACH (Resources for Enhancing Alzheimer's Caregiver Health), to examine the effectiveness of various interventions to strengthen family members' capacity to care for individuals with AD. Thus far, the study has recruited over 1200 caregiver/care recipient pairs at six different sites across the country to participate in 12 different interventions. REACH is designed to show us what works to support caregivers and at what cost; we anticipate that the first findings from this trial may be available within the next several years. The NIMH is supporting a major project called the Clinical Anti-psychotic Trial of Intervention Effectiveness for Alzheimer's Disease (CATIE-AD) designed to help identify effective treatments for behavioral problems in AD, to help reduce the burden of care for both providers and families.

The process of translating basic science findings into clinical interventions is a challenging but critical component of AD research. One promising finding of recent basic research efforts was the ability of an immunization strategy to prevent or reverse formation of amyloid plaques in mouse models of AD. The initial clinical trial of this AD vaccine approach, conducted by the Irish pharmaceutical company Elan Corporation, plc and not an NIH-funded trial, was halted earlier this year when a number of participants on the experimental treatment were found to have brain inflammation. Despite the unfortunate outcome of this trial, the science on which the study was based will provide a base on which to build better and safer strategies for arresting or reversing the brain lesions of AD. In collaboration with the National Institute of Neurological Disorders and Stroke (NINDS), NIA has already issued a Request for Applications (RFAs) and funded a number of studies to better understand the science underlying the vaccine approach.

The RFA with NINDS is one of many collaborations in which the NIA participates as part of its program of AD research. NIA frequently co-sponsors RFAs and Program Announcements (PAs) with other institutes, and leads an inter-institute AD working group. With NINDS and NIMH, NIA co-sponsors the Cognitive and Emotional Health Project (Healthy Brain Project), the goals of which are to assess the current state of knowledge of predictors of cognitive and emotional health with age and to accelerate the pace of scientific advances in these fields. NIA also collaborates with other institutes, including NINDS and the National Institute of Child Health and Human Development, to conduct preclinical toxicology tests on compounds that may be effective against AD, and, with the National Center for Complementary and Alternative Medicine, co-sponsors a large clinical trial of ginkgo biloba as an AD preventive.

Fifteen years ago, we did not know any of the genes that could cause AD, and we had no idea of the biological pathways that were involved in the development of brain pathology. Now, we know the three major genes for early onset disease and one of the major risk factor genes for late-onset disease, and we have extensive knowledge of pathways leading to the development of AD's characteristic amyloid plaques in the brain. Ten years ago, we could not model the disease in animals. Today, transgenic mice are an invaluable resource for modeling amyloid plaque development in the brain and in testing possible therapies. Five years ago, we did not have any prevention trials funded and had no ways of identifying persons at high risk for the disease. Now, we have seven ongoing prevention trials, and scientists are identifying persons at high risk for developing AD by imaging, neuropsychological tests, and structured clinician interviews. And as recently as one year ago, we did not understand anything about how plaques and tangles relate to each other. Now, through the creation of the first double transgenic mouse to produce both plaques and tangles, we know that plaques in the brain can influence the development of tangles in brain regions susceptible in AD.

It is difficult to predict the pace of science or to know with certainty what the future will bring. However, the progress we have already made will help us speed the pace of discovery, unravel the mysteries of AD's pathology, and develop safe, effective preventions and treatments, to the benefit of older Americans.

Thank you, Senator Mikulski, for giving me this opportunity to share with you our progress on Alzheimer's disease. I would be happy to answer any questions you may have.

PREPARED STATEMENT OF CONSTANTINE G. LYKETSOS, M.D.

Good morning. Let me begin by thanking you Senator Mikulski for holding this very important hearing and for inviting me to testify this morning. This is just one more example of your constant and invaluable leadership in the fight to conquer Alzheimer's disease. I am delighted to be here with my friends from the Alzheimer's Association and want to acknowledge that organization's ongoing staunch advocacy here in Baltimore, in Maryland, and across the country, on behalf of people with Alzheimer's disease and their families. It is an honor for me to serve as chair of the Medical/Scientific Advisory Committee to the Central Maryland Chapter of the Association.

I also want to acknowledge Dr. Richard Hodes, Director of the National Institute on Aging (NIA) and his Deputy Director, Dr. Judy Salerno who is also with us today. They are leading a rapidly escalating effort, not just at NIA but also across institutes throughout NIH, to find the answers to Alzheimer's disease. They have attracted the best scientists to this important enterprise—now they need the money from Congress to take advantage of the scientific opportunities that have been created.

I speak to you today as a scientist and medical school professor at Johns Hopkins, as a physician who has cared for thousands of patients with Alzheimer's disease and their families, but also as the spouse of a woman whose grandmother suffered greatly before dying from this horrible illness. Alzheimer's has touched me personally, as it has so many here in this room today.

Most of us are likely to live at least until age 65, and many of us will live to age 85 or older. In fact, when I ask audiences to whom I speak how many expect to live to be 85 years, almost everyone raises their hand. Those of us living to 65 have 1-in-10 chance, and those of us living to 85 have as much as a 1-in-3 chance of developing Alzheimer's disease or a related condition. Therefore, the specter of Alzheimer's disease is a very personal one. It will affect us all directly or indirectly in the years to come.

Research is an essential part of the battle to conquer Alzheimer's disease. The ultimate goal must be to find treatments that will cure, prevent, or delay this illness. At the same time, we must focus our energies on research designed to improve the lives of the 4 million victims currently alive in the United States, and the countless others worldwide, for whom a prevention or cure will come too late. And, we must research ways to improve the lives of the caregivers, who are just as affected by the disease. It is critical that we as a Nation dedicate adequate resources to this effort.

That is why I so strongly endorse S. 2059, the Alzheimer's Disease Research, Prevention and Care Act of 2002, which you and Senator Kennedy have introduced to assure adequate resources for the essential research that must be done in the immediate years ahead. And by reauthorizing and expanding the Alzheimer's grant programs to the State, you will help assure that what we learn about Alzheimer's disease is translated to better access, care and treatment for people with the disease and their caregivers.

Your bill provides the essential stimulus to help the goal set by the Alzheimer's Association and endorsed by your colleagues on the Senate Appropriations Committee, to increase Federal funding for Alzheimer's research to \$1 billion per year.

Good research is costly, but the potential return on investment is huge. For a Congress concerned about controlling health care spending and guaranteeing the future of Medicare, finding a way to stop Alzheimer's disease must be a very high priority.

We at Johns Hopkins are proud to be at the forefront of both research and care of Alzheimer's and related disorders. Our memory disorders clinical program, one of the first ever established in the United States, spanning the several Johns Hopkins medical institutions and our affiliated long-term care facility, Copper Ridge, provides diagnostic evaluations and ongoing care "from diagnosis to the end of life" for thousands of patients with Alzheimer's every year.

We now know a great deal about evidence-based, systematic care for people with Alzheimer's disease, which can make a substantial difference in the lives of our patients and their families. Current treatments, which include a combination of medications, counseling, and a variety of other interventions have been shown to alleviate symptoms, to delay institutionalization, and to delay the course of this progressive illness. While the cure is not yet on hand, what we have today can be of great benefit when properly applied. While it is beyond the topic of this particular hearing, I would emphasize the urgency of incorporating this knowledge into health and long term care policy. That includes adding a prescription drug benefit and chronic care coverage to Medicare.

ALZHEIMER'S RESEARCH OPPORTUNITIES AND PRIORITIES

We are here today to discuss the research needs for the future. These can be summarized in a few broad strokes.

First, we need to better understand the biology of Alzheimer's disease. This involves laboratory work to understand the complex mechanisms involved in the brain degeneration, the hallmark of the condition. My colleagues at the NIA-funded Johns Hopkins Alzheimer's Disease Research Center are working hard every day in this effort.

Second, we need to better characterize risk and preventive factors for Alzheimer's disease through epidemiologic research. Research at Johns Hopkins has already led to the identification of estrogen and NSAIDs (non-steroidal anti-inflammatories) as possible preventive factors, and to the implementation of prevention studies using both of these treatments.

Much more needs to be known about the risk and preventive factors for dementia so as to develop effective preventions or treatments. Currently under investigation are the role of genes, nutrients, medications (prescription and over the counter), and other biological factors (e.g., homocysteine) in the development of AD. Recent research out of Hopkins indicates that the incidence of Alzheimer's peaks and then declines in late life. This research also suggests that a large proportion of the population may not be susceptible to the development of Alzheimer's. The reason for this non-susceptibility likely includes some combination of protective factors involving both genes and environment. Identification of protective genes and their gene products would be a major breakthrough.

One area of enormous potential, where basic biological, epidemiological, and clinical research overlap, is the growing evidence of the connection between vascular disease and Alzheimer's. We already know about risk factors and effective prevention of vascular disease. If we can better understand these connections, we may be on the path to prevention of Alzheimer's as well. This is a particularly important field of research for people of color, particularly African-Americans and Hispanics, who are at higher risk of vascular disease.

Third, we need to improve the accuracy and ease of the diagnosis of Alzheimer's disease. In academic medical centers such as Johns Hopkins, we can achieve diagnostic accuracy of over 90 percent in many cases; but that level of diagnostic accuracy is not realized in most clinical settings. We know now that Alzheimer's disease has a long pre-clinical phase, where the disease is damaging the brain, but when there are no symptoms. At present we do not have the capability of diagnosing the disease in these very early stages of its development. Yet, accurate diagnosis is critical to effective treatment. In addition, the earlier the diagnosis, the greater the effectiveness of treatments. Also, diagnostic tests that are accurate may provide clues to the biology of the illness. A wide range of diagnostic tests, including cutting edge imaging techniques of the living brain, must be evaluated for this purpose.

Fourth, we need to improve our understanding of the full range of clinical manifestations of the disease. Recent research from our group has found that as many

as 90 percent of patients develop non-cognitive symptoms such as depression, agitation, delusions, hallucinations, and distressing behaviors. Most of these are a direct consequence of the brain damage that the disease brings about. These are very troubling symptoms which dramatically worsen the lives of patients, burden caregivers, and can rapidly lead to early institutionalization. They also create some of the most difficult challenges for residential facilities caring for persons with dementia. Effective management of the symptoms can have a wide range of benefits, for the patient, the family, and the formal care system.

Fifth, we must substantially and immediately increase research into the treatments of Alzheimer's disease. The most exciting possibility comes from recent knowledge of the pre-clinical phase of Alzheimer's disease. It turns out that the disease is damaging the brain for many years before the onset of any symptoms. This offers an opportunity to intervene and stop or slow it before symptoms occur. That is the key to preventing Alzheimer's. One estimate indicates that if the disease could be delayed by 5 years, the number of people suffering from the disease would be reduced by half. To this end the National Institute of Aging has initiated prevention studies to find out whether certain medications can prevent the onset of Alzheimer's symptoms and other Institutes are now joining NIA in that effort.

CLINICAL STUDIES AT JOHNS HOPKINS

At Johns Hopkins we are proud to have a leadership role in these clinical studies. By way of example, I mention today the Alzheimer's Disease Anti-inflammatory Prevention Trial or ADAPT in which I have a leadership role. ADAPT is designed to find out whether healthy people 70 and older without memory symptoms, who have a family history of Alzheimer's, are less likely to develop the disease if treated with non-steroidal anti-inflammatory medications. This study has already enrolled 600 people at six sites nationwide, one of which covers the Baltimore-Washington area. We eventually plan to enroll a total of 2,400 participants over the next year-and-a-half. I would like to take a moment to acknowledge the presence in the room my staff of the ADAPT-Baltimore team who are working extremely hard in this critical study. This, along with other studies investigating other potential treatments or preventions such as estrogen, and ginkgo, are in the field recruiting participants.

These sorts of studies are very expensive, each costing anywhere between \$15 and \$25 million, but they are the only way we will find the safe and effective way to stop Alzheimer's. Each study takes several years to complete and involves scores of clinicians as well as thousands of participants. The most promising studies involve healthy seniors, or people with mild cognitive impairment, who must be enrolled in sufficient numbers and over long enough periods of time for the symptoms of Alzheimer's disease to emerge. These studies also require substantial investment in outreach efforts to recruit and retain enough study participants, including particularly participants from the diverse ethnic and cultural backgrounds affected by Alzheimer's disease.

The success of these studies depends not just on adequate funding, but also on educating our seniors about the availability of these studies and encouraging them to consider participation in them. That is another reason, Senator Mikulski, why this hearing and your very visible leadership is so important.

In addition to these efforts to find ways to prevent Alzheimer's, laboratories at universities worldwide and several pharmaceutical companies are working aggressively to find effective medications for the treatment of Alzheimer's disease. Already we have several FDA-approved treatments that have some benefits for disease symptoms. Redoubling laboratory efforts at drug discovery and bringing potential new medication treatments to clinical trials where we can assess their safety and efficacy should be a major undertaking over the next few years.

Equally important to finding ways to treat the cognitive symptoms, we need to evaluate further treatments for the non-cognitive symptoms of the disease. That will yield great benefits for patients and families and for long term care providers. For example, in the Depression in Alzheimer's Disease Study funded by the National Institute of Mental Health, we have recently found that alleviation of depression may delay the functional decline of the disease.

We must not limit ourselves to medication treatments since a variety of other interventions greatly benefit patients. With our affiliate, the Copper Ridge Institute, we are investigating the benefits of several non-medication treatments for Alzheimer's patients and their caregivers. Increased funding in this area, thus far primarily supported by the Alzheimer's Association, will also be necessary.

Finally in the area of treatment, we need to be sure that we can deliver treatments where they are needed. I specifically want to mention the long-term care environment. Currently, about one-quarter of people with Alzheimer's disease, perhaps

as many as one-third, live in residential care facilities. We have known for many years that a very large portion of the nursing home population has Alzheimer's or another dementia. We are only now finding this out about assisted living. In our Maryland Assisted Living Study (funded by the National Institute of Mental Health), our initial findings indicate that as many as two-thirds of residents suffer from memory disorders and that the detection and treatment of these disorders in that environment is sorely lacking. It is critical that we understand better the presence and course of Alzheimer's in assisted living and that we deliver the most effective available treatments to this population of patients as well.

In summary, and with my deep appreciation for your inviting me to speak at this hearing, I would like to strongly emphasize that Alzheimer's is a disease that affects us all at a personal, an economic, and a societal level. Research is the key that will allow us as society to manage this scourge. Redoubling efforts of research in the laboratory, looking for risk factors and protective factors, improving diagnosis, understanding of the course of the disease, and developing a wide range of preventive and other treatments, with a special emphasis on drug discovery, and improving care must be our mission for the future.

PREPARED STATEMENT OF HENRIQUE S. NYANKALE

Mr. Chairman, and Members of the Committee:

My name is Henrique Shadrack Nyankale, a resident of the State of Maryland. I am a graduate student in Public Administration at George Mason University, and an Intern of the Metropolitan Washington Council of Governments in the Management and Operations Division in the Office of the Corporation Counsel, in Washington, DC. I am pleased to have the opportunity to present my testimony on the scourge of the Alzheimer's disease. I speak for my family and for the 4 million innocent Americans who found themselves victims of this disease. Remember our former President Ronald Reagan, who after serving this Nation so well, finds himself suffering from the scourge of this terrible disease called Alzheimer's?

My interest in health policy advocacy began on the first week of June, 2002, when I was taking a Health Policy course from the Washington Health Policy Institute at the Law School of George Mason University in Arlington Campus, Virginia. In discussing the devastating effects of various diseases, the word Alzheimer's brought back bad memories to me, because my father-in-law died from this disease at the age of 65 in Johannesburg, South Africa. Before his death, our family experienced first-hand the physical, emotional and financial hardships of caring for him. We did not have access to any resources to help improve his condition, nor did we get any support to help us care for him at home. It was excruciating for us to watch his health deteriorate before our eyes each day. When I came to the U.S., I thought I came to heaven where no diseases penetrated. To my surprise, my health policy research has uncovered the shocking truth about the ugliness of the Alzheimer's disease. In my State—Maryland—alone, there were nearly 80,000 Americans who had been diagnosed with Alzheimer's disease in the year 2000. This number is expected to jump to approximately 130,000 within the next 28 years, a 62.5 percent increase, according to the U.S. Census Bureau's PPL-47 Report.

Mr. Chairman, nationwide, the statistics that show the growing trend in the numbers of people who are, and will be diagnosed with Alzheimer's disease in the next 28 years are: 1. Disheartening to the coward, 2. Challenging to the courageous, and 3. Meaningless to the unconcerned, who happily lays in the false lull of the Alzheimer's silent killing tactics. Anyone interested in disproving my fear of—and challenge from—this looming national catastrophe should refer to the State-by-State current and predicted figures and percentages of Americans with Alzheimer's from the U.S. Census Bureau's PPL-47 Report developed by Paul R. Campbell, or find it at www.census.gov (and look for PP-47). The above statement presents an opportunity to both the Senate and House of Representatives. It is a boat of opportunity that both Houses may choose to board and save the millions of Americans who are being held hostage by the Alzheimer's or leave the Nation at the mercy of this ominous, ravaging and unmanned health destroyer called Alzheimer's disease.

The results of the 2001 studies by Harold Rubin (www.therubins.com), have shown that: (1) Alzheimer's disease is the most prevalent neurodegenerative disease, and is considered non-reversible; (2) In 1999 alone, 44,536 Americans died of Alzheimer's disease, making this disease the 8th leading cause of death nationwide, as reported in the National Vital Statistics Reports (Vol. 49, No. 8). According to the Centers for Disease Control, although Alzheimer's had ranked 12th among the leading causes of death in 1998, the 1999 death toll (indicated above) from Alzheimer's jumped in ranking from 12th to the 8th position, surpassing the totals for other various major causes of death, including motor vehicle accidents and cancer.

The June 7, 2001 Report of the American Medical Association indicates that Alzheimer's disease will reach epidemic proportions within the next few decades. This report issued an ominous prediction that the incidence of Alzheimer's disease will more than triple within the next 30-40 years, as life expectancy continually increases and as the 76 million baby boomers in the U.S. begin reaching age 65 in the year 2011. By 2050, the number of Americans aged 65 and older will have doubled from the current 35 million to 70 million people.

Currently, approximately 4 million Americans are suffering from Alzheimer's disease, with annual costs approaching more than \$100 billion. The Alzheimer's Association predicts that the current 4 million Alzheimer's figure will exponentially increase to 14 million by the middle of this century, unless a cure or prevention is found.

The Alzheimer's Association also reports that more than 7 of 10 people with Alzheimer's live at home with almost 75 percent of the home care provided by family and friends, which causes a great deal of physical, emotional and financial hardship, not only to the victims, but also to their loved ones who must devote extensive time and effort to care for them. At the national level, the impact of Alzheimer's disease on American businesses is alarming. Business costs associated with this disease totaled \$33 billion in 1998 and nearly doubled to \$61 million in 2002. Currently, businesses spend over \$36 billion annually in lost productivity as employees are absent from work to provide care to their loved ones with Alzheimer's disease.

Let us look back in history for the precursor to the current bill. In 1982, the Alzheimer's Association established a Pilot Research Grant Program. In the same year, U.S. Representative Bill Lowery introduced legislation asking Congress to declare National Alzheimer's Disease Week. Later that year, President Ronald Reagan signed legislation designating Thanksgiving week as the National Alzheimer's Disease Awareness Week.

In response to the 1983 Alzheimer's Association's launching of its "National Program to Conquer Alzheimer's Disease" presented before the Select Committee on Aging, Congress allocated \$22 million for a government-wide effort to find the cause and cure for Alzheimer's disease. President Ronald Reagan approved the creation of a task force to oversee and coordinate scientific research on Alzheimer's disease. A year later, and for the first time, Congress declared the month of November the "National Alzheimer's Disease Month." In 1984, in recognition of the need to find cure for Alzheimer's disease, Congress allocated \$44 million to Alzheimer's research, and through the National Institute on Aging, authorized support of the first five Alzheimer's Disease Research Centers.

In 1986, Research grants were established to fund independent Alzheimer's research projects. With the assistance of the Alzheimer's Association, the National Institute on Aging and the Warner-Lambert Pharmaceutical Company initiated a clinical trial to test the THA on Alzheimer's patients. Since then, progress has been made in finding drugs that can slow down or cure a few early symptoms of Alzheimer's. To highlight the devastating nature of Alzheimer's disease, the U.S. Office of Technology Assistance, published the first report on Alzheimer's disease entitled "Losing a Million Minds: Confronting the Tragedy of Alzheimer's Disease and Other Dementias." But we still have a long way to go in hunt for cure of Alzheimer's disease. In 1994, former President Ronald Reagan announced that he has been diagnosed with Alzheimer's disease.

Efforts towards establishing legislation on Alzheimer's picked up momentum when in 1999, a bipartisan Congressional task force on Alzheimer's disease was launched by Representatives Edward Markey (D-MA) and Christopher Smith (R-NJ). The bill's momentum was generated by Senators Barbara Mikulski and Edward Kennedy. Senator Mikulski sponsored the bill and both she and Senator Kennedy introduced it to the Committee on Health, Education, Labor and Pensions on March 21, 2002. Progress has been marked by the Committee's passing of the bill, S. 2059, Alzheimer's Disease Research, Prevention and Care Act 2002. The introduction of this bill in the Senate has sparked off similar action in the House of Representatives where on June 25, 2002, Representative Edward Markey (D-MA) introduced a similar bill—H.R. 4606—to the House Committee on Energy and Commerce where it is awaiting the committee's consideration.

Looking at the progress this bill has made in both Houses, I am encouraged. I am happy to hear that on Wednesday, June 26, 2002, the Committee on Health, Education, Labor and Pensions passed S. 2059. Advocates of this legislation are happy to hear that the bill has been placed on the Senate Legislative Calendar under the General Orders, Calendar No. 483, for consideration by the full Senate. My heartfelt gratitude goes to Senators Mikulski and Kennedy for sponsoring this bill. I also thank Senators Cochran (R-MS), Hutchinson (R-AR), Miller (D-GA), and

Dodd (D-T) who mustered courage and co-sponsored this bill. I also thank all the other Senators who voted for it.

The purpose of the bill S. 2059, Alzheimer's Disease Research, Prevention and Care Act of 2002, is to foster the development of innovative models of care for persons with Alzheimer's disease and their caregivers, particularly the underserved minority, rural and low-income populations. It reauthorizes the Alzheimer's Disease Demonstration Grant Program to assist individual States and calls for establishing an Alzheimer's Disease Cooperative Study Group. It also boosts Alzheimer's Disease Prevention Initiative by authorizing \$1.5 billion for the National Institute on Aging. If it passes the full Senate and Congress makes it into law, it will have tremendous impact on healthcare delivery in our Nation. Its benefits will include increasing the federal government's commitment to research on preventing and finding a cure for Alzheimer's disease. The bill will provide the most comprehensive legislation to date, expanding critical programs and services, particularly to underserved communities.

On the other hand, if this bill is not made into law, a number of grave consequences will result. First, as life expectancy continues to increase and the 76 million baby boomers in our Nation begin reaching age 65 by 2011, the number of Americans stricken with Alzheimer's disease will increase exponentially, as predicted by experts. As a result, the number of Alzheimer's victims requiring full-time care will also increase tremendously. Billions of dollars will have to be spent by millions of caregivers as they take care of their Alzheimer's-stricken family members. Business operations will be affected, as increasing numbers of employees will be forced to provide home care to their loved ones who suffer from Alzheimer's disease, resulting in increased employee absenteeism and lost productivity. Insurance costs will be so high that many people will not be able to afford health and long-term care for this debilitating disease.

I, therefore, urge you all to support the passage of the bill S. 2059, the Alzheimer's Disease Research, Prevention and Care Act of 2002. Please vote in favor of this bill and help those who are skeptical realize the importance of continued research and support to victims and families plagued with Alzheimer's disease. Research and statistics make frightening predictions about the impact of Alzheimer's disease on our society, beginning within the next 10 years and skyrocketing within the next 30-40 years.

Since Alzheimer's disease attacks mostly the aging population, we should remember that as more Americans (including many of us here today) approach age 65 and beyond, the chances of being struck by Alzheimer's increases dramatically. Let us not "age in fear." Please remember that we are now able to use the Hubble telescope to scan outer space and see some never-before-seen formations of new stars, galaxies, planets and supernovas. We, the Americans, are attempting to land spacecrafts on comets. We are now able to walk in space and conduct technical repairs in space. We do all of this in the hopes of improving our lives in the future. Because we are able to do these things, we can challenge ourselves, look into the future, and sense the bleak and devastating impact of this dreaded disease and find ways and means to conquer Alzheimer's disease. Let us use our knowledge of science and medicine and advanced technology as the tactical weapons we can deploy to defeat and conquer Alzheimer's disease, so that we may all "age gracefully" and not "in fear."

Mr. Chairman, the future of the 4 million Americans with Alzheimer's disease is in the hands of all the Senators who are listening to this testimony or are reading it from whatever source. They are the ones who have the power to vote for the passage of this bill S. 2059 into an Alzheimer's legislation. Therefore, the longevity of, or short-lived life of the 14 million Americans predicted to have Alzheimer's disease by the year 2030, is also in the hands of the Senators and Representatives. Your vote will show whether you are for or against Alzheimer's victims living longer.

Past efforts should give us an impetus to surge forward and find ways to detect, confine, control, and eliminate the Alzheimer's disease. Please vote for the passage of the bill S. 2059, will you?

Thank you, Mr. Chairman.

[Whereupon, at 11:47 a.m., the hearing was adjourned.]