Federal Under-Investment Severely Hinders Alzheimer’s Research

Dear Friends and Colleagues:

As we end another year, I am reminded of the solemn responsibility that continues to lie ahead of us. For those of us in the field of Alzheimer’s research, we never lose sight of a disease that keeps on challenging, testing, and opposing our knowledge. A friend recently asked me: if, when I entered this field of science 30 years ago, I would have imagined that by this time we would be further along in our pursuit of a cure or perhaps found a way to treat the disease with success. Well, in my heart, of course, I wish we could have, by now, found a cure, prevention, or a way to slow the progression of a disease that disrupts the lives and families of so many. However, it is not due to lack of will or wisdom on the part of researchers. Instead, I strongly believe the single most hindering factor has been lack of federal funding to support innovative investigators, many of whom are working on multiple fronts to find better ways to diagnose and detect the disease before the onset of clinical symptoms. The key: to intervene and prevent the disease before brain damage is so severe that it is difficult to reverse the destruction.

If we take a look at research funding for Alzheimer’s versus other comparable illnesses, the facts are plain to see: federal funding for cancer research is about $6 billion annually; cardiovascular disease research is about $4 billion annually; HIV/AIDS research is about $3 billion each year and Alzheimer’s disease research is approximately $450 million annually. However, Congress recently approved a boost in funding; Alzheimer’s research funding is up to $498 million for 2012. This is an uptick, yet hardly enough. Many experts, including the chief medical and scientific officer of the Alzheimer’s Association, believe that Alzheimer’s requires a federal budget of $2 billion annually in research funding in order to achieve the goal of effective treatment or prevention within the next two decades.

Please join us in our mission to eliminate Alzheimer’s. As you’ll read below, the Silberstein Foundation has provided us with a very generous funding opportunity. Please would you make a monetary gift through this campaign to support life-changing research at our Center so that generations to follow will know a world without Alzheimer’s.

Alzheimer’s disease is the sixth-leading cause of death in our country, and the only cause of death among the top 10 that cannot be prevented or cured. No longer can we postpone the challenge posed by this disease. The will, the wisdom, the courage, the collaborative nature, the desire to overcome this disease resides within all of us at the Comprehensive Center on Brain Aging. Many of us in this field have dedicated our lives to finding a cure, determined to put this disease in the history books. We ask you to help us and contribute to this cause.

I end with this from President John F. Kennedy: “We choose to go to the moon. We choose to go to the moon in this decade and do the other things, not because they are easy, but because they are hard, because that goal will serve to organize and measure the best of our energies and skills, because that challenge is one that we are willing to accept, one we are unwilling to postpone, and one which we intend to win...”

Regards,

Ralph A. Nixon, M.D., Ph.D.
Director, Comprehensive Center on Brain Aging

CALL FOR ACTION

Unprecedented Donor Campaign to Increase Funding for Alzheimer’s Research at NYU Langone

THE SILBERSTEIN FOUNDATION, the Comprehensive Center on Brain Aging’s founding partner and major benefactor for the last three decades, has pledged to match every dollar donated to Alzheimer’s research and care at NYU Langone Medical Center by December 31, 2012 — doubling the impact of donor support. Never before has an opportunity like this been presented to us.

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How to Minimize and Mitigate Wandering

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Are Major Barriers for People With Dementia and Their Caregivers

World Alzheimer Report 2012 Reveals Stigma and Social Exclusion Are Major Barriers for People With Dementia and Their Caregivers

Co-authored by Mary S. Mittelman, Dr.P.H., the World Alzheimer Report 2012 recently released by Alzheimer’s Disease International (ADI) reported that a multinational survey indicated that nearly one in four people in the early stages of dementia hide or conceal their diagnosis, citing stigma as the main reason. Furthermore, 40 percent of people with dementia report not being included in everyday life. Nearly two out of three respondents, both people with the disease and family caregivers, feel that there is little or no understanding of dementia in their countries, according to the report. “Our study underscores the need to raise awareness and do more in terms of educating the public about dementia to reduce stigma and help people with dementia and their family members to be included in society and live the best lives possible,” said Dr. Mittelman.

The report provides recommendations to enable governments and societies to overcome stigma, including greater public education, as nearly half of the survey respondents indicate education and awareness was a huge priority. Another key point is to encourage people with dementia to share their experiences and to ensure that they are included in everyday activities with family and friends.

The report also reveals:

- 24% of people with dementia and more than one in 10 caregivers (11%) said they concealed the diagnosis of dementia. Those under the age of 65 said they believed they might face special issues in their workplace or children’s schools.
- Nearly 60% of the people with dementia indicated that friends are the most likely people to avoid them or lose contact after diagnosis.
- A quarter of caregivers (24%) feel there are negative associations in their country about caregivers of people with dementia while a similar number (28%) feel they have been treated differently or avoided.
- Both people with dementia and caregivers stated they had stopped themselves from forming new close relationships, except with people in the same situation as their own, as it was too difficult.

Continued on page 6.
Novel Alzheimer’s Disease Clinical Trials Now Open for Enrollment

Medical research has led to milestone discoveries that make our lives healthier and better. In just the last few years, scientists have made significant strides in gaining a deeper understanding of dementia and aging-related brain disorders. Since its establishment 30 years ago, research has been at the fundamental core of the Silberstein Alzheimer’s Institute, both in terms of basic research done in a laboratory as well as with volunteers within a clinical trials setting.

Laboratory research can only be fully appreciated and the potential fully realized through clinical studies. The success of many of the new treatments available to Alzheimer’s patients today is due, in part, to the ongoing participation of volunteers who contribute to furthering the possibility for prevention and a cure. Some of our patients elect to participate in research studies, known as clinical trials, because they want to help contribute to research efforts with the hope that they may help others in the future.

“We use clinical trials as a way to determine what works best to help patients. The purpose of a trial is to determine the safety of a drug, treatment plan or procedure and to measure its potential benefits. Drugs in clinical trials undergo strict regulatory requirements through the Food and Drug Administration (FDA) before they become approved to be used in human participants in a trial,” says Steven H. Ferris, Ph.D., Director of the Alzheimer’s Disease Center (ADC) and the Clinical Trials Program at the Silberstein Alzheimer’s Institute.

Pioneering research at the Silberstein Alzheimer’s Institute promises to have a measurable impact on the lives of current and future Alzheimer’s patients. But a lack of volunteers for Alzheimer’s clinical trials is significantly slowing progress toward the development of new treatments. According to the Alzheimer’s Association, “Recruiting and retaining trial participants is now the greatest obstacle, other than funding, to developing the next generation of Alzheimer treatments.”

Alzheimer’s Disease Trials Open for Enrollment at NYU

Clinical Phase II Study to Evaluate the Impact of Biomarkers of Resveratrol Treatment in Patients with Mild to Moderate Alzheimer’s Disease

This study will assess the effect of resveratrol (a plant-derived compound found in red wine and the skin of red grapes) treatment on Alzheimer’s disease biomarkers,* as well as resveratrol safety and tolerability in people with mild to moderate AD. Compelling evidence shows that caloric restriction can improve health by activating a class of enzymes known as Sirtuins. Resveratrol mimics the positive effects of caloric restriction by activating the same enzymes. It is hoped that resveratrol will be beneficial in delaying or altering deterioration of memory and function. Qualifying participants age 50 and up with AD will have approximately 10 visits at the clinic in one year.

*Biomarkers offer one of the most promising paths for detection and treatment. They include proteins in blood or spinal fluid, genetic variations (mutations) or brain changes detectable by imaging.

Alzheimer’s Disease Neuroimaging Initiative - 2

The purpose of this study is to build upon the information obtained in the original Alzheimer’s Disease Neuroimaging Initiative (ADNI1) and ADNI-GO (Grand Opportunity; a study funded through an NIH grant under the American Recovery and Reinvestment Act), to examine how brain imaging technology can be used with other tests to measure the progression of mild cognitive impairment (MCI) and early Alzheimer’s disease. ADNI2 seeks to inform the neuroscience of early Alzheimer’s disease. ADNI2 will enroll subjects who are diagnosed with MCI or AD. Participants may be eligible whether they are free of memory impairment or have been diagnosed with MCI or AD. Participants will have 8-12 visits over five years.

For more information on these trials please contact
Dana Pogorelec at 212-263-5708
dana.pogorelec@nyumc.org
Giuseppe Agugliaro at 212-263-5845
giuseppe.agugliaro@nyumc.org.

Study to Evaluate the Effect of Anti-amyloid Therapy on Cognition and Function in Prodromal (Pre-Dementia) Alzheimer’s Disease.

This two-year study will evaluate the effect of a beta amyloid lowering monoclonal antibody (gantenerumab) versus placebo. Accumulation of a particular protein, beta amyloid, is thought to be related to the progression of Alzheimer’s disease (AD) and begins well before the onset of AD dementia and probably even before any cognitive decline associated with AD. It is therefore reasonable to think that the benefit of anti-amyloid therapy (gantenerumab) may be greater if initiated before prominent symptoms of AD, such as dementia, manifest. This study will enroll subjects who do not yet meet a diagnosis for Alzheimer’s dementia, but have findings that characterize the predementia or prodromal phase of AD.

For information on this trial, contact
Dr. Antero Sarreal
1-800-521-8367, 845-398-6532, or 845-398-5582
asarreal@nki.rfmh.org.

This study takes place at Nathan Kline Institute (NKI) in Rockland County. NKI has a strong academic collaboration with the Department of Psychiatry of New York University.

RESEARCH SPOTLIGHT

Following are clinical studies now open for enrollment. We encourage our readers to call our study coordinators to learn about these trials and whether they may be eligible to participate.

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Continued from page 1.

Bruce Silberstein, President of the Silberstein Foundation comments, “Our family has been a part of the fight against Alzheimer’s for nearly four decades. In the mid 1970s, my mother was diagnosed with Alzheimer’s. Seeing the effect that the disease was taking on her and the impact on our family was devastating. Yet, my father was so touched by the compassion- ate care she was receiving from the team at NYU that he donated a significant sum to the Medical Center for Alzheimer’s research so that countless others in our position may be helped. For the last 35 years, our family has continued this commitment, and, we solidify on this journey with the hope that one day our children and grandchildren may never have to suffer from a disease that robs us of our minds, our memories, and our lives.”

Earlier this fall, the Silberstein Matching Gift program was launched in order to further expand Alzheimer’s research and clinical capabilities as well as caregiver support programs at NYU and to increase the public’s awareness of the disease through community outreach. Mr. Silberstein added, “The only way to reach our ultimate goal is through research. Today’s research programs are under-funded due to insufficient federal grants. Collectively, we need to pledge our support so that one day the generations that follow will know a world without Alzheimer’s.”

Since inception, the Silberstein Alzheimer’s Institute has been at the forefront of research advances — from advancing the scientific community’s understanding of the genetic and molecular structure of the disease to developing state-of-the-art brain imaging and clinical assessment tech- niques. Its investigators continue to be top-ranked in the areas of clinical treat- ment, early diagnosis, genetic and molecular causes, and drug discovery. In 2007, in order to bring research findings directly to the patient, the Institute inaugurated the Pearl I. Barlow Center for Memory Evaluation and Treatment providing an integrated approach to the care of memory impairment and age-related brain disorders. Since then, many other specialty clinics have been formed including one that specializes in Lewy Body Dementia.

Please join the Silberstein Foundation in the fight against Alzheimer’s disease by making a contribution before December 31. To make a gift please contact Maura Larkin in the Office of Development at 212.404.3469 or email maura.larkin2@nymcu.org.

### Continued from page 1.

In addition to these trials and other on- going studies, in early 2013 we anticipate starting several investigational studies that will test the safety and efficacy of potential therapies for Alzheimer’s dis- ease at the prodromal (pre-dementia), mild and moderate stages. These studies will include several new drugs that may reduce the accumulation of brain amyloid, or may reduce the other protein involved in Alzheimer’s, abnormal tau. There will also be two studies seeking to delay or prevent Alzheimer’s in normal individuals. These future studies may involve novel or intravenous medication, or non-pharmacologic treatment and will last anywhere from 2-18 months or five years, depending on the program.

All investigational research studies require the consent of a participant; a screening visit to determine eligibility for a specific study; as well as participation of a study partner — a friend or relative who can accompany volunteers to clinic visits. The partner should have regular contact with the volunteer and be able to attend all study visits.

If you are considering participation in a trial, the following information may be helpful to you:

- The decision to participate is com- pletely your choice and you should never feel obligated or forced. You should know as much as you can about the study and always feel comfortable asking your doctor any questions.
- Your confidentiality is always and com- pletely protected as stated by regula- tion: information gathered from the trial may be used, but your name and specific health information will never be used outside of the trial setting.
- You can stop being a participant at any time during the period of the study.
- Your doctor may choose to end your participation if your health deteriorates.
- You will be made aware of any modifi- cations in the study.

It has been shown that whether or not an experimental treatment is effective, individuals who participate in clinical studies appear to do better than people in a similar stage of their disease who are not enrolled in a trial. The scientific basis for this advantage includes the general high quality of care provided during clini- cal studies.

The ADC at the Silberstein Alzheimer’s Institute is one of 30 Alzheimer’s disease research centers in the U.S. supported by the National Institute on Aging (NIA). Pharmaceutical companies and the National Institute for Aging Alzheimer’s Disease Cooperative Study (ADCS), a national clinical trials consortium, sponsor these clinical studies. NYU has successfully participated in many trials, thereby contributing to the development of new Alzheimer’s treatments.

### Facts

#### Did You Know?

**Physical Activity Can Boost Mental Wellness ... and Add Years to Your Life!**

As an older adult, regular physical activity is one of the most important things you can do for your health. It can prevent many of the health problems that seem to come with age. It also helps your muscles grow stronger so you can keep doing your day-to-day activities without becoming dependent on others. The American Heart Association recommends 30 minutes of moderate activity, but three 10-minute periods of activity are almost as beneficial to your overall fitness as one 30-minute session.

- **Physical activity boosts mental wellness:** Exercise increases the flow of oxygen which directly effects the brain. Your mental acuity and memory can be improved with physical activity. Regular physical activity can relieve tension, anxiety, depression and anger.

- **Physical activity improves physical wellness:** It enhances your immune system and decreases the risk of developing diseases such as cancer and heart disease. Becoming more active can lower your blood pressure and also boost your levels of good cholesterol.

- **Physical activity prolongs your optimal health:** Without regular physical activity, the body slowly loses its strength, stamina and ability to function well. And for each hour of regular exercise you get, you’ll gain about two hours of additional life expectancy, even if you don’t start until middle age. Moderate exercise, such as brisk walking, for as little as 30 minutes a day has proven health benefits and helps delay or prevent chronic illnesses and diseases associated with aging.

**Sources:** Centers for Disease Control and Prevention; National Institute on Aging; American Heart Association
Here We Are Amongst Ourselves

Clinical social worker Ursula Auclair facilitates group therapy sessions at the Center.

"Inhale through your nose and exhale through your mouth. Again... breathe in, breathe out."

This isn’t the start of a yoga class. Instead, it is the first few minutes of a therapy group at the Comprehensive Center on Brain Aging. About a dozen men and women diagnosed with early stage Alzheimer’s disease sit around a large table, ready to begin their 90-minute session with Ursula Auclair, a clinical social worker at the Center. After a stretching exercise routine and singing two songs chosen by group members, the session begins with each member saying his/her name. The discussion that follows changes from week to week, depending on what is important to the group at that time — this might include reactions to world events, personal experiences that occurred during the week, illness issues, hopes and fears. “Group members find a sense of community, a place where they can confide in others who understand and share their struggles. Participation in this type of group is an antidote to the withdrawal and isolation from social interaction often experienced by persons with dementia,” says Auclair. “For the caregivers, it is equally important to have others who understand them and to have the chance to form new close relationships, which can often be difficult to develop at this stage of life and when caring for a person with this disease,” adds Auclair. At the Comprehensive Center on Brain Aging, several groups are offered. Facilitated by a clinical geriatric social worker, the two therapy groups for persons with dementia offer participants a safe, welcoming environment for emotional or self-expression. A unique opportunity for caregivers is a peer-led support group that meets at the same time as the early stage AD group so that the caregiver and the person with Alzheimer’s may attend his/her own group. One group for caregivers is under the auspices of the Alzheimer’s Association and is also led by a clinical social worker. Presently, the Center is exploring the feasibility of starting a new group for people over the age of 55 who have experienced the loss of a friend or family member to Alzheimer’s and may have diminished mobility and interest in an initiative in reaching out on their own to make new friends and join interesting activities. The decision to seek counseling is personal. Too often, people don’t get help because they feel ashamed, guilty, or embarrassed. By deciding to get help, you make the choice to feel better and improve your life. Alzheimer’s Disease Groups Presently in Session at NYU are:

- Early Stage AD Therapy Group: Meets on Thursdays from 12 noon to 1:30 PM
- Early-to-Mid Stage and Lewy Body Disease Therapy Group: Meets on Fridays from 2:00 PM to 3:30 PM
- Caregiver Support Groups: The Center offers two different groups. One is peer-run and meets on Thursdays from 12 noon to 1:30 PM; the other is a traditional group with a counselor which meets on Mondays from 10:00 AM to 11:30 AM. To join one of these groups or for more information, please call Ursula Auclair, LCSW, at 212-263-2245.

A Poem by Frank Brenner, June 2010

An early stage group participant in appreciation of his experience

It is great to be here with you
This is really an amazing crew
What an exciting season it has been
With people I had never before seen
A group very unusual in scope
Where many really like to talk
There are great executives galore
Even one that has been in jail before
A few come in their very best suit
And one has jumped round in a parachute
There is an actress of great renown
And some that like to paint the town
And to me it means so much
To sit next to a really great judge
To witness so much courage, so much hope
Has greatly helped my ability to cope
And I hope that it is not too late to state
That the leadership is really great!

World Alzheimer Report 2012 Reveals Stigma and Social Exclusion Are Major Barriers for People With Dementia and Their Caregivers

Continued from page 3.

The report is based on a global survey of 2,500 people across more than 50 countries. The main aim of the survey was to record individual experiences of stigma by people with dementia and family caregivers; and help identify whether national dementia plans have had an impact on reducing stigma. Just over 50 percent of the respondents with dementia had Alzheimer’s disease and the others had other dementias, including vascular and frontotemporal dementia and mild cognitive impairment. Slightly less than half of the total number were under the age of 65. Current research suggests that the negative perceptions of individuals and society regarding dementia may lead to the isolation of people with dementia and their caregivers, and also reinforce and extend isolation caused by the effects of the disease. Thus, the report concludes that stigma could be a major barrier to finding solutions for the problems related to Alzheimer’s disease and other dementias, including low rates of diagnosis and service utilization. Adds Dr. Mittelman, “It is essential to conduct more research to determine the most effective ways to counteract all aspects of stigma. More widespread availability of opportunities that include — rather than segregate — people with dementia, can do much to reduce the false beliefs and stigma that currently impede diagnosis, treatment, service delivery and the dignity and personhood of people with dementia.”

Dr. Mittelman and the clinicians on her staff have been developing, conducting and evaluating psychosocial interventions to support people with Alzheimer’s disease and their family members for more than two decades. Dr. Mittelman is the Director of the Psychosocial Research and Support Program at the Silverstein Alzheimer’s Institute, and Research Professor in the Department of Psychiatry at NYU Langone Medical Center.

Co-authoring the study with Dr. Mittelman was Nicole Batsch, who has more than 15 years of experience in developing aging and dementia programs across the United States. Ms. Batsch is currently a Ph.D. candidate at King’s College London in the Institute of Gerontology, focusing on dementia.
Experts within our Psychosocial Research and Support Program at the Silberstein Alzheimer’s Institute offer the following suggestions:

It is difficult enough to receive a diagnosis of AD. It can also be difficult to tell other people about it. One is aware of and fears the stigma of the symptoms and being associated with the person who is suffering from them.

People have mixed feelings about letting anyone know that they or a family member have been diagnosed with Alzheimer’s disease. They fear the negative reactions of others and would prefer to act as though everything is fine. You may want to tell the people to whom you feel close soon after you find out about the diagnosis so that they can be supportive and understanding, rather than puzzled by the changes they have observed.

It is important to inform professionals such as lawyers and physicians so that they can provide appropriate services and health care.

- Close family members and friends may have already noticed subtle changes and will be grateful for an explanation or be relieved not to have to pretend anymore. Telling them may deepen your relationship in ways you may appreciate.
- Expect that some of the people you tell about the diagnosis may not believe it is true. Alzheimer’s disease is in many ways “invisible,” particularly in its early stages. Often the person with the diagnosis and close relatives may have trouble accepting that the person has an illness.

Some people who care about you will be eager to find out how they can be helpful, and if you tell them candidly what you want, will be glad to provide it. You may feel uncomfortable about asking for or accepting help, but support is essential to your quality of life and that of the person with Alzheimer’s disease.

Don’t be surprised if some friends and family members distance themselves. It may be that they don’t know how to respond or don’t want to be around someone who is ill. With time, many will become more comfortable around the person with dementia and want to maintain their relationship with him or her and with you.

If people ask questions about what the diagnosis means, share what you know and tell them about books or websites that you have found helpful. You may want to tell close family members about education programs or support groups for relatives of people with Alzheimer’s disease.

Try not to isolate yourself or the person with Alzheimer’s disease. Don’t assume everyone will shun you. Try to find activities that have been designed for people in the early stage of Alzheimer’s disease and their family members. New friendships may develop.

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### Salmon with Cilantro Pesto

**INGREDIENTS:**
- 4 salmon fillets (about 4 ounces each), rinsed and patted dry
- 1/4 cup sliced almonds

**COOKING INSTRUCTIONS:**
Preheat the oven to 400°F. Line a baking sheet with aluminum foil or lightly spray with cooking spray. In a food processor or blender, process the pesto ingredients for 15 to 20 seconds, or until slightly chunky. Place the fillets about 2 inches apart on the baking sheet. Spread the pesto evenly over the top of the fillets. Sprinkle with 1/4 cup almonds. Bake for 10 to 12 minutes, or until the fish flakes easily when tested with a fork.

**NUTRITIONAL ANALYSIS PER SERVING:**
- Calories: 206
- Total Fat: 9.5 g. / Saturated Fat: 1.5 g.
- Trans Fat: 0.0 g. / Polyunsaturated Fat: 3.0 g.
- Monounsaturated Fat: 4.0 g.
- Cholesterol: 66 mg. / Sodium: 129 mg.
- Fiber: 1 g. / Protein: 28 g.
- Carbohydrates: 2 g. / Sugar: 0 g.
- Dietary Exchanges: 3 1/2 lean meat

Recipe Source: American Heart Association

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A key to healthy aging is eating a heart-healthy diet full of lean protein, fruits, vegetables, and whole grains. Fish is a good alternative to high-fat meats. Certain types of fish are rich in omega-3 fatty acids, which can lower blood fats called triglycerides. The highest amounts of omega-3 fatty acids are found in cold-water fish, such as salmon and mackerel.
What causes early-onset Alzheimer’s?
Of all the people who have Alzheimer’s disease, only about five percent develop symptoms before age 65. Many people with early-onset Alzheimer’s have a parent or grandparent who also developed the disease at a younger age. A significant proportion of early-onset Alzheimer’s is linked to three genes — APP, PSEN 1 or PSEN 2. The genetic path of inheritance is much stronger in early-onset Alzheimer’s. If you have a genetic mutation in one of these three genes it would be very likely for you to develop Alzheimer’s before age 65. The inheritance pattern for these three genes differs from that of another important genetic factor in Alzheimer’s, the APOE gene. A variant of this gene increases risk mainly for later-onset Alzheimer’s disease and does not guarantee that Alzheimer’s will develop at older ages.

I’ve heard that certain vitamin supplements, such as B-12, can help improve or deter memory loss. Is that true?
There have been many studies on this subject and as far as I’m aware, there’s no conclusive evidence that B-12 supplements or any other vitamin or herbal supplement can enhance memory. I would place more emphasis on the importance of older adults eating healthy, well-balanced meals containing fruits, vegetables, low-fat proteins (fish instead of red meat), legumes, and grains. Select low sodium foods and eat smaller portions. A heart-healthy diet may be as good for your brain as it is for your heart.

Letters to the Editor: We encourage you to write to us — voice your comments and feedback on articles you have read in our newsletters. We will select a few for publication in each issue. Letters may be submitted via email to camy.sleeman@nyumc.org. We reserve the right to edit letters for length.