FROM THE DIRECTOR

NAPA — Historic Legislation for the Alzheimer’s Cause

Dear Friends and Colleagues:

Earlier this year, President Obama signed into law the National Alzheimer’s Project Act (NAPA) after it had received unanimous support in both the state and House of Representatives. This is a historic legislative victory for the Alzheimer’s cause in the United States. As a country, we have made monumental strides in Alzheimer’s research especially within the last decade, and with the signing of this Act, we now send a strong message — the United States has made Alzheimer’s disease (AD) a major legislative platform and priority.

NAPA will create a national strategic plan to address and overcome the rapidly increasing crisis of Alzheimer’s. Over the last several years, the Alzheimer’s Association has been leading the influence in appealing to Congress and the White House to pass NAPA. NAPA’s goal is “to accelerate the development of treatments that would prevent, halt or reverse the course of Alzheimer’s” and “improve the early diagnosis of Alzheimer’s disease and coordination of the care and treatment of citizens with Alzheimer’s.” This is of significant importance as the baby boomers are aging and will soon be entering the years of highest risk for the disease.

One of the elements of the Act is to reinforce research efforts to detect brain changes that occur before symptoms are noticeable and to develop drugs to prevent or substantially delay symptoms. Our work at the COE focuses on understanding the underlying causes of Alzheimer’s and identifying effective, innovative treatment strategies to be implemented at a stage of the disease when treatment can have a profound impact on functional status and rate of decline — when there is the most chance of preventing decline rather than intervening at an advanced state. Scientific evidence points to the fact that Alzheimer’s disease begins within the brain 15-20 years before clinical manifestations. By the time a patient is diagnosed, irreversible brain damage has already taken place. Therefore, our research at the Center of Excellence has fundamentally focused on ways in which we can diagnose Alzheimer’s before the clinical symptoms are evident. As you will read in the pages ahead, we are working on methods to pinpoint the disease well before cognitive impairment sets in.

As we all know, AD brings with it enormous societal cost, in terms of medical care, caregiving support, as well as in-home and out-of-home nursing costs. And alongside the national crisis, is the private suffering, which all too often is overshadowed by the enormous public hardship. We, at the Center of Excellence on Brain Aging, view Alzheimer’s both as a clinical disease that needs to be eradicated, as well as one that has a very private side — the suffering, hardship and distress we see in the faces of our patients and their loved ones each day. For the elderly, it is a disease that robs them of their independence and dignity; for their loved ones, it is a disease that tears apart the fabric of a family. To all of you, we pledge to continue our pursuit for a cure.

With the enactment of NAPA, this reality may be more within our reach than ever before.

Regards,

Ralph A. Nixon, M.D., Ph.D.

Director

Center of Excellence on Brain Aging

FEATURE STORY

New Simple Test for Early Detection of Dementia

Alzheimer’s disease and related disorders that affect cognitive abilities are significant public health problems and early diagnosis is often difficult due to the lack of sensitive and brief dementia screening instruments. This deficiency will become more apparent with the implementation of health care reform. As stipulated in the Affordable Care Act, clinicians will be required to evaluate older patients for cognitive impairment as part of a patient’s annual wellness examination. If an in-depth clinical workup needs to be performed, the standard workup for Alzheimer’s disease includes a medical history and physical examination, as well as laboratory tests, radiology, and neuropsychological testing. The lab tests employed in a standard workup are intended to rule out other causes of dementia, such as nutritional deficiencies, infection, metabolic disorders, drug effects, etc.

Increasingly, biomarker tests which detect biological signs of a disease, such as MRI (magnetic resonance imaging), PET scans (positron emission tomography) — a nuclear medicine imaging technique) and cerebrospinal fluid (CSF) are utilized to increase the diagnostic likelihood that AD is present; however, some biomarker analyses are invasive, uncomfortable, expensive, and continued on page 2.
New Simple Test for Early Detection of Dementia

Continued from Page 1

may not be readily available to rural areas, underserved communities, under-insured individuals or developing countries, thus making them impractical for broad use.

Clearly, there exists a need for sensitive and specific cognitive screening tools that are valid, easy to administer, and minimally time-consuming, given the time constraints in most clinical settings.

Developed by James E. Galvin, M.D., M.P.H., Director, the Pearl S. Barlow Center for Memory Evaluation and Treatment, the AD8 (Ascertained Dementia 8) test for dementia is a brief, valid, and reliable informant-based measure that is sensitive and predictive in discriminating non-demented older adults from those with even mild forms of dementia from all causes. It is an efficient, inexpensive, culturally sensitive and socially acceptable test that has been biologically validated to correspond to biomarkers of Alzheimer’s disease.

The AD8 is a simple test with eight “yes” or “no” questions, which a friend or relative can complete in just a few minutes in the comfort of their own home instead of a clinical setting. The questionnaire looks for changes in memory and thinking over time that interfere with day-to-day functioning. It has an extremely simple scoring system, with two or more “yes” answers suggesting the need for further diagnostic testing (see box below). In the absence of an informant, the patient can complete the form as a self-rating tool with equal effectiveness.

To determine the validity of the AD8 questionnaire vis-à-vis other screening tests, Dr. Galvin and team assessed 257 men and women ages 50 to 91 for dementia. The researchers used the AD8 and several traditional screening tests. The participants also had brain scans and spinal taps to find any biomarkers of the disease. The researchers then looked at how well the tests detected people who also had these Alzheimer’s biomarkers. The AD8 worked as well or better than the longer and more complex tests currently used by doctors.

“Often, Alzheimer’s disease remains undiagnosed in its earliest stages and one reason is the lack of brief screening tools that can adequately detect the earliest signs of impairment,” says Dr. Galvin, lead author of the study. “We developed this brief informant interview test which distinguishes individuals with very mild dementia from those without dementia and is sensitive to the earliest signs of cognitive change as reported by an informant.” The AD8 is highly correlated with the industry’s gold standard, the CDR (Clinical Dementia Rating) and neuropsychological tests. Indications are it is sensitive and specific enough to serve as an initial screen with primary care physicians.

Dr. Galvin adds, “for treatment to have the greatest impact, we need to recognize individuals in the earliest stages of the disease. Early, accurate detection is important not only in terms of a patient benefiting from therapies, pharmacological and non-pharmacological, but also extending quality of life. Furthermore, it provides families, patients and caregivers the opportunity to plan for the future.”

The AD8 is available in English, French, Spanish, Chinese, Korean and Tagalog with versions being prepared in Japanese, Indonesian, Norwegian, and Czech. Results of Dr. Galvin’s research, conducted at Washington University School of Medicine in St. Louis, were recently published online in the journal, Brain.

For more information, please contact the Pearl S. Barlow Center for Memory Evaluation and Treatment at 212.263.3210.

The AD8 Dementia Screening Test

Answer YES, NO or DON’T KNOW to these eight questions: Remember, “Yes, a change” indicates that there has been a change in the last several years caused by cognitive (thinking and memory) problems.

1. Problems with judgment (e.g., problems making decisions, bad financial decisions, problems with thinking)
2. Less interest in hobbies/activities
3. Repeats the same things over and over (questions, stories, or statements)
4. Trouble learning how to use a tool, appliance, or gadget (e.g., VCR, computer, microwave, remote control)
5. Forgets correct month or year
6. Trouble handling complicated financial affairs (e.g., balancing checkbook, income taxes, paying bills)
7. Trouble remembering appointments
8. Daily problems with thinking and/or memory

Score 1 for each yes. A score of 2 or more suggests the need for further testing.

DID YOU KNOW?

Alzheimer’s Disease International (ADI) released a new report highlighting the soaring cost of dementia and the need for action by policy makers and governments across the globe. World Alzheimer Report 2010 is a culmination of the most comprehensive, current data. Findings include:

- The total estimated worldwide costs of dementia are $604 billion in 2010.
- Dementia significantly affects every health and social care system in the world.

For more information, please visit www.alz.co.uk.
Path of Progress: Researchers Target Novel Treatment Aimed at Restoring Cellular Waste Recycling

An abnormal build-up of proteins such as amyloid beta in the brains of Alzheimer’s disease patients is often the focus of research into finding the source and ultimately a cure for Alzheimer’s and other neurodegenerative diseases. However, amyloid, though important, is just one of the many toxic proteins that cause brain cell dysfunction.

In the brains of people with Alzheimer’s disease, affected neurons progressively accumulate a variety of obsolete and damaged proteins, including the amyloid and tau proteins that are diagnostic for the disease. Although cells have an internal recycling system for breaking this protein “trash” into re-usable bits, this recycling center, called autophagy (“self-eating”), seems to be faulty in Alzheimer neurons. The undigested trash eventually clogs the neuron’s long extensions that communicate with other brain cells, obstructing the communication needed to form memories and to preserve survival of the neuron itself.

A recently published study, reported online in the journal Brain, conducted by researchers at NYU Langone Medical Center and the Nathan S. Kline Institute for Psychiatric Research, sheds light on a possible therapy aimed at restoring the recycling system’s capacity to digest protein trash. Using Alzheimer’s mouse models, the researchers re-activated the sluggish recycling system by genetically removing a factor (cystatin B) that normally keeps digestion from becoming over-active. This protein inhibits enzymes called cathepsins, which break down proteins in lysosomes (compartments in the cell that digest and recycle material). This strategy achieved the desired effect of increasing the activity of digestive enzymes and effectively eliminating much of the waste protein that would have otherwise clogged the neurons. Beyond markedly reducing amyloid accumulation in and outside of the cells in brains of the Alzheimer model mice, the treatment prevented the severe memory decline that develops in this mouse model and restored learning and memory functions.

“These findings represent ‘proof of concept’ evidence that targeting the faulty recycling system in the Alzheimer’s disease brain could be a promising innovative approach to therapy for this devastating disease,” said Ralph A. Nixon, professor in the Departments of Psychiatry and Cell Biology at NYU Langone Medical Center and director of the Center for Dementia Research at the Nathan S. Kline Institute for Psychiatric Research. Investigators caution that more study is required and that this genetic strategy is not practical for a clinical setting. “The goal now will be to further investigate drug-based approaches to achieve a similar effect on the brain’s faulty recycling system,” said Dr. Nixon, who is also director, Center of Excellence on Brain Aging and the Silberman Alzheimer’s Institute at NYU Langone Medical Center.

Unavoided by Hazardous Waste

A clue to how Alzheimer’s and other disease davey can be found in lysosomes, which process waste inside the cell. Faulty waste management leads to aggregation in nervous cells.

In a recent interview published in The Wall Street Journal, Dr. Nixon commented that traditional drug development in Alzheimer’s disease is taking too narrow an approach by just focusing intensively on the buildup of amyloid beta-protein in the brain. Amyloid, although important, is just one of the many toxic proteins that swell the neurons when the lysosomal system breaks down. Ideally, Dr. Nixon says, “Drugs could repair the defective mechanism intended to eliminate all toxic proteins before damage is done to the brain.”

Gladys González-Ramos, Ph.D. 1954-2010

The NYU Parkinson and Movement Disorders Center joins the Parkinson’s community in mourning the loss of Gladys González-Ramos, Ph.D., center co-founder, as well as co-founder and co-director of the NYU/JCC wellness program. A highly respected national leader in the Parkinson’s field, Dr. González-Ramos died on December 22, 2010 after a long and courageous battle with cancer. She was Associate Professor of Social Work at the NYU Silver School of Social Work since 1985 where she received her M.S.W and Ph.D. Additionally, Dr. González-Ramos served as adjunct Associate Professor of Neurology at the NYU School of Medicine.

A gifted teacher and mentor, inspired by needs identified through the experiences of her parents and other persons living with Parkinson’s disease, Dr. González-Ramos co-founded the NYU Parkinson and Movement Disorders Center alongside Dr. Alessandro Di Rocco. Far-reaching in her commitment to provide support to those affected, she worked tirelessly to develop programs designed to provide access for all persons with Parkinson’s to the right care at the right time throughout the continuum of care.

Additionally, Dr. González-Ramos was co-founder and assistant director of the National Parkinson Foundation’s (NPF’s) Allied Team Training for Parkinson (ATTP) professional education program for interdisciplinary teams, and co-director of the NPF national outreach program, Community Partners for Parkinson Care (CPP)/National Parkinson Care Network. She was a sought-after national speaker and a published scholar, co-authoring her most recent book, HealthConnect: A Practical Guide to Community Outreach — winner of the Wilmer Rich Shields Award from the National Council on Foundations. For her many contributions and accomplishments, Dr. González-Ramos received several distinguished honors, such as the NPF Allied Team Faculty Award for Leadership; the NYU Silver School Alumni Award; and accolades from the NASW-NYC/Latino Social Work Task Force and the Puerto Rican Family Institute.

We remain committed to honoring her memory by continuing her work on behalf of people and families affected by Parkinson’s disease. Two donation funds have been established: The González-Ramos Community Lecture Series and The NYU Silver School of Social Work Annual Gladys González-Ramos Memorial Lecture Series.

For more information, contact Amy Lemen at 212-263-7282.

MindMatters FALL/WINTER 2010
A publication of NYU Langone Medical Center | Center of Excellence on Brain Aging

IN MEMORIAM

Gladys González-Ramos, Ph.D.
1954-2010

The NYU Parkinson and Movement Disorders Center joins the Parkinson’s community in mourning the loss of Gladys González-Ramos, Ph.D., center co-founder, as well as co-founder and co-director of the NYU/JCC wellness program. A highly respected national leader in the Parkinson’s field, Dr. González-Ramos died on December 22, 2010 after a long and courageous battle with cancer. She was Associate Professor of Social Work at the NYU Silver School of Social Work since 1985 where she received her M.S.W and Ph.D. Additionally, Dr. González-Ramos served as adjunct Associate Professor of Neurology at the NYU School of Medicine.

A gifted teacher and mentor, inspired by needs identified through the experiences of her parents and other persons living with Parkinson’s disease, Dr. González-Ramos co-founded the NYU Parkinson and Movement Disorders Center alongside Dr. Alessandro Di Rocco. Far-reaching in her commitment to provide support to those affected, she worked tirelessly to develop programs designed to provide access for all persons with Parkinson’s to the right care at the right time throughout the continuum of care.

Additionally, Dr. González-Ramos was co-founder and assistant director of the National Parkinson Foundation’s (NPF’s) Allied Team Training for Parkinson (ATTP) professional education program for interdisciplinary teams, and co-director of the NPF national outreach program, Community Partners for Parkinson Care (CPP)/National Parkinson Care Network. She was a sought-after national speaker and a published scholar, co-authoring her most recent book, HealthConnect: A Practical Guide to Community Outreach — winner of the Wilmer Rich Shields Award from the National Council on Foundations. For her many contributions and accomplishments, Dr. González-Ramos received several distinguished honors, such as the NPF Allied Team Faculty Award for Leadership; the NYU Silver School Alumni Award; and accolades from the NASW-NYC/Latino Social Work Task Force and the Puerto Rican Family Institute.

We remain committed to honoring her memory by continuing her work on behalf of people and families affected by Parkinson’s disease. Two donation funds have been established: The González-Ramos Community Lecture Series and The NYU Silver School of Social Work Annual Gladys González-Ramos Memorial Lecture Series.

For more information, contact Amy Lemen at 212-263-7282.
COE Honors Distinguished Scientist Blas Frangione, M.D., Ph.D.

With more than half a century of dedicated scientific study, Blas Frangione, M.D., Ph.D., Professor of Pathology and Psychiatry and head of the Alzheimer’s Disease Research Center at NYU School of Medicine, has been a driving force of the Alzheimer’s research program within NYU Langone and has played a pivotal role within the research community globally. Paying tribute to this international leader of Alzheimer’s science, the Center of Excellence recognized Dr. Frangione’s lifetime contribution to continued progress against Alzheimer’s disease and presented him with the COE’s Scientific Achievement Award at a recent event. Colleagues and faculty of NYU Langone gathered to honor Dr. Frangione as a pioneering researcher, mentor, educator and friend.

Dr. Ralph A. Nixon offered words of appreciation and gratitude to Dr. Frangione for his dedication to the field of amyloid diseases in general and Alzheimer’s disease in particular, and the pioneering path he has forged. Additionally, Dr. Nixon concluded the ceremony by announcing that in honor of Dr. Frangione and his commitment to training, educating and mentoring the next generation of researchers, the COE has established the Blas Frangione Junior Investigator Merit Award, which will be presented to one deserving scientist annually.

Awards and Recognition

Moses Chao, Ph.D., Named President-Elect of the Society for Neuroscience
Moses Chao, Ph.D., professor of cell biology, physiology and neuroscience, and psychiatry at NYU School of Medicine, and a member of the Molecular Neurobiology Program at the Skirball Institute of Biomolecular Medicine, was named president-elect of the Society for Neuroscience (SfN), one of the largest organizations of scientists and physicians devoted to advancing understanding of the brain and nervous system. As the society’s next president, Dr. Chao will focus on increasing public awareness of neuroscience research; the inequality of gender in higher positions; and the necessity of more basic research to solve neurodegenerative diseases.

Dr. Chao’s previous SfN positions held include secretary, chair of the Committee on Committees, senior editor of the Journal of Neuroscience, and chair of the Program Committee. A published author in many research publications, Dr. Chao has also served on numerous editorial boards including the Journal of Neuroscience, Molecular and Cellular Neuroscience and the Journal of Biological Chemistry. As his research has centered on the mechanism of action of neurotrophic factors, Dr. Chao has been an advisory board member for many institutions, including the Christopher & Dana Reeve Foundation, the Simons Foundation, the Vollum Institute and St. Jude’s Cancer Center.

Efrat Levy, Ph.D., Receives Zenith Fellows Award from Alzheimer’s Association
Efrat Levy, Ph.D., an associate professor in the Departments of Psychiatry and Pharmacology at the NYU School of Medicine and the Center for Dementia Research at the Nathan S. Kline Institute for Psychiatric Research, has received a Zenith Fellows Award from the Alzheimer’s Association. This is the Association’s largest and most prestigious regular research grant, including a maximum award of $450,000 over three years. Dr. Levy has received this grant for her research proposal entitled, “Transgenic models of the anti-amyloidogenic activity of a mutant form of amyloid-beta.”

Although age is the most powerful risk factor for Alzheimer’s disease, a small fraction of people develops the disease because of genetic mutations that trigger amyloid-beta fibril accumulation. In collaboration with colleagues in Italy, Dr. Levy has previously sequenced the DNA of a patient with early onset Alzheimer’s disease and found a mutation in the amyloid-beta protein gene. The Alzheimer’s Association Zenith Fellows grant will allow her to continue to study this mutation in order to attempt to develop a drug that can prevent the buildup of plaques in the brain.

Dr. Levy’s hypothesis is that two abnormal copies of a naturally occurring human gene containing the recently identified mutation result in early onset Alzheimer’s disease, but one normal copy and one mutated copy is actually preventative.

American Association for Geriatric Psychiatrists Honors Barry Reisberg, M.D., with Distinguished Scientist Award
Annually, the American Association for Geriatric Psychiatrists (AAGP) presents its Distinguished Scientist Award to an AAGP member who has advanced the field of geriatric psychiatry, in terms of lifetime scientific accomplishment as well as dedicated mentorship contributing to the success of junior researchers in the field of geriatric psychiatry. This year, Barry Reisberg, M.D., at the AAGP’s Annual Meeting in San Antonio, Texas, in March.

Dr. Reisberg has received a similar award, the Lifetime Achievement Award for Research in Alzheimer’s Disease from the Alzheimer’s Association and the International Conferences on Alzheimer’s Disease (ICAD), in 2004. Though he has been honored with many other distinguished awards, these two are of special meaning as they honor and recognize his lifetime accomplishments.
Talking to Children About Alzheimer’s Disease

Alzheimer’s is a disease that impacts the entire family, especially the emotional well-being of a family. Life changes dramatically when a family member has Alzheimer’s disease. Often, children suffer in silence through the changes that occur. At the Barlow Center, we encourage caregivers to take the time to have thoughtful and caring discussions with children and grandchildren who may be affected.

The degree to which children and teens are troubled by the disease depends on who within the family has it — a parent, grandparent or other relative. Other factors include how close the child is to the person and where the person lives (in the same home, assisted living or nursing home, out-of-state, etc.). Children and teens often have feelings of sadness related to the changes they see in a loved one’s personality and behavior; confused or afraid about why the person is behaving differently; worried that the disease may be contagious. There also may be emotions of anger and frustration leading to guilt — guilt for getting angry or being short-tempered with the relative. Sometimes, jealousy may also set in because of the increased amount of time and attention that is given to an Alzheimer’s patient. These are all considered “normal” in the spectrum of emotions. It is important to validate children’s feelings and help them cope with the situation.

Ways to help children and teens cope:
- Offer comfort and support
- Provide opportunities for them to express their feelings and let them know their feelings are normal
- Educate them about the disease and encourage them to ask questions
- Respond honestly to questions
- Activities that can help and be done as a family:
  - Go for a walk
  - Do household chores together
  - Listen to music, dance or sing
  - Look at old photographs
- Read a favorite book or newspaper
- Create a scrapbook or photo album about the person
- Make a family tree
- Watch a movie
- Keep a journal together

For more information, please visit the Alzheimer’s Association’s website: Kids & Teens section.

Source: Alzheimer’s Association; www.alz.org.

Chicken and Mushroom Fricassee

INGREDIENTS:
- 1 tbsp. olive oil
- 1 carton (10 oz.) white button mushrooms, rinsed and quartered
- 1 cup leeks, split into quarters, then sliced into small squares and rinsed well
- 1 cup potatoes, peeled and diced
- 1 cup pearl onions, raw or frozen
- 3 cups low-sodium chicken broth
- 1 lb. skinless chicken legs or thighs
- 2 tbsp. fresh herbs (such as parsley and chives), rinsed, dried, and minced (or 2 tsp. dried)
- 1 tsp. lemon juice
- 1 tsp. cornstarch
- 2 tbsp. fat-free sour cream
- 1/2 tsp. salt
- 1/4 tsp. ground black pepper

INSTRUCTIONS:
1. Preheat oven to 350° F.
2. Heat olive oil in a medium-sized, heavy-bottom roasting or braising pan (a large sauté pan with a metal handle will work as well).
3. Add mushrooms to pan, and cook until golden brown, about 3–5 minutes. Add leeks, potatoes, celery, and pearl onions, and continue to cook until the vegetables become soft, about 3–5 additional minutes.
4. Add chicken broth to the pan, and bring to a boil. Add chicken legs to the pan, cover, and place in the heated oven for about 20 minutes or until the chicken legs are tender when pierced with a fork (to a minimum internal temperature of 165° F).
5. When chicken legs are tender, remove legs from the pan, return the pan to the stove top, and bring the liquid to a boil. Add herbs and lemon juice.
6. In a bowl, mix the cornstarch with the sour cream, and add to the pan. Bring back to a boil and then remove from the heat.
7. Season with salt and pepper, and pour 1 cup of vegetables and sauce over chicken.

NUTRITION INFORMATION PER SERVING:
- Calories: 242
- Total Fat: 9 g.
- Cholesterol: 42 mg.
- Sodium: 430 mg.
- Carbohydrates: 24 g.
- Potassium: 807 mg.
- Protein: 20 g.

*Recipe source: Keep the Beat Recipes: Deliciously Healthy Dinners, from the National Heart, Lung, and Blood Institute.

Healthy Eating, Healthy Living!
From that day forward, our lives were invaded. Then was diagnosed with Alzheimer’s disease. However, soon thereafter, he had an MRI, and thought was that he may have a brain tumor. Something was dreadfully wrong, my first spoke at our anniversary party and I realized this was a sign of the times. Later, when he all our married years. I imagined that perhaps national stability. He had never been like that in dependent. He lacked confidence and emo-

Editor: When did you begin to notice that your husband may have Alzheimer’s disease?

Mrs. K.: It was at our 50th anniversary cel-

Editor: Were there any tell-tale signs prior to this event?

Mrs. K.: When I look back upon the years leading up to that time, I realize that some of the symptoms had begun to take shape. Louis had become very nervous, anxious and overly dependent. He lacked confidence and emo-
tional stability. He had never been like that in all our married years. I imagined that perhaps this was a sign of the times. Later, when he spoke at our anniversary party and I realized something was dreadfully wrong, my first thought was that he may have a brain tumor. However, soon thereafter, he had an MRI, and then was diagnosed with Alzheimer’s disease. From that day forward, our lives were invaded.

About Dr. Barry Reisberg

Barry Reisberg, M.D., is a professor of psychiatry, NYU School of Medicine; Director of the Zachary and Elizabeth M. Fisher Alzheimer’s Disease Education and Resources Program; and Director of the Clinical Care of the National Institute on Aging (NIA)-funded Alzheimer’s Disease Center within the Silberstein Alzheimer’s Institute, NYU Langone Medical Center.

Dr. Reisberg has directed research on Alzheimer’s for the past three decades and is recognized as a leader in the field. He has contributed fundamentally to the current medical and scientific understanding of Alzheimer’s disease including the initial description of many of the most important symptoms of AD and its characteristic course. These findings are being related to neurologic, physiologic, neuroendocrine, physical and pathologic features as well as to fundamental biomolecular factors. Additionally, assessment instruments developed by Dr. Reisberg contributed to the worldwide development of all three major current pharmacological treatments for AD, i.e., memantine (Namenda); risperidone (Risperdal); and rivastigmine (Exelon worldwide development of all three major current pharmacological treatments for AD, i.e., memantine (Namenda); risperidone (Risperdal); and rivastigmine (Exelon physical and pathologic features as well as to fundamental biomolecular factors.

Editor: Could you expand on that last comment?

Mrs. K.: Louis was a brilliant, honorable, gentle man. He always had a tremendous sense of responsibility. He was born during the Depression, and at the age of seven, he began working shelving egg crates and selling magazines to tenants door-to-door, in walkup apartments, to make a sale of one cent per magazine... in order to provide for his family. Louis entered City College when he was 15, then enlisted in the Navy and was stationed in the South Pacific. He returned to the U.S. to work, again in order to help his family, and then completed his college education. Upon receiving his degree, he entered the realm of finance, as Director of Research at Standard & Poor’s. From there, he held several executive positions at New York’s top brokerage houses. He was a man of integrity, righteous in every way. Having served his country in two wars, World War II and the Korean War, he was stalwart, devoted and unwaveringly committed to his family, his marriage, his country and to the principles by which he lived.

Louis was my rock. Today, my rock is a pebble. The disease has robbed me of my husband, stolen Louis’ identity, and pillaged our life. I have no better way to describe Alzheimer’s other than an “identity theft disease.” We are the victims of this “crime.” I thought I had my memories but even those have become tainted by the devastation caused by the dise-

Editor: We’re very appreciative of your benevolence and the legacy gift that you have made to Dr. Reisberg’s program. What inspired you to provide this gift?

Mrs. K.: We decided to contribute to Dr. Reisberg’s program in order to further his pioneering research studies, in breadth and depth. This ties in with the fact that I want to do my part in fighting this disease so that the generations that follow us may know a world without Alzheimer’s. I believe strongly that the only way to eradicate this disease is to continue the path of perseverance in research. And we all know: scientific discovery is fueled by funding. Clearly, it is too late to help Louis, but we can help others in the not-too-distant future. Louis and I have nieces and nephews and they have their children; we pray that this disease never strikes them, but if it should, we hope there will be treatment options that will be beneficial... better yet, we hope there will be a cure.

Editor: How have you made peace with the disease?

Mrs. K.: I don’t think I could ever make peace with the disease, but I hope that through our funding we can make a difference.

Editor: What advice would you provide to those in a similar situation?

Mrs. K.: You can’t do it alone. Reach out for help — from your friends, family, community — and if you have the means, hire the help you need at home. Make the time to do things outside of the house and keep in contact with your friends. Take care of your own self and well-being, and try to stay fit. When you are at home, read, watch a movie, immerse yourself in some-
thing completely different to allow your mind a chance to escape. Most of all, try not to let the depression and grief over-
whelm you and steal your strength.

Editor: What would be your “take away” message?

Mrs. K.: Enjoy your life and appreciate the gift of good health. I often reminisce about our first 50 years of married life. Louis and I traveled around the world. We visited 104 different countries in 35 years. The irony of it all is now I am on an unimaginable journey — the sorrow, the sadness, the suffering. Hold on to your memories dearly and remember the person you love in his/her glory.
A Story of Hope

A mother’s love for her child is unconditional. For a single mother, this love is all too often enveloped in great sacrifice, deep responsibility, and at times, sinking despair. For Norma this was certainly the case as she raised young Pamela. But as the years passed, the weight of responsibility shifted and before long, Pamela was the one who had to take care of her mother. This was especially true as Norma aged — her life began to show signs of weariness, she withdrew socially, depression set in, and she leaned heavily on Pamela for support of every kind. Being an only child, Pamela was in the role of guardianship. Given the demands of a professional career and her own adult life, Pamela continued to care for her mother. Then, as her mother entered her seventies, Pamela began noticing changes — Pamela would ask her questions, and receive vague or nonsensical answers — but she attributed this to normal signs of aging. As Pamela says, “I was so used to covering up for my mother’s behavior my whole life that this just became a natural extension... quite frankly, I was in denial.” She was in denial of the fact that her mother was displaying early signs of Alzheimer’s disease.

Time went on. The medical problems with her mother were increasingly apparent and Pamela was now struggling with the demands placed on her from all angles — her mother, her marriage and motherhood. It was then that Pamela and her husband decided to consult with an elder care attorney. As they began that process, simultaneously, Pamela stumbled upon a pamphlet for the Pearl S. Barlow Center for Memory Evaluation and Treatment that contained information on early signs of dementia. Pamela read the handout and realized that these early signs of dementia were those that her mother had been exhibiting. Without haste, she called the Barlow Center and made an appointment for her mother.

At their first consultation in September, Norma saw Stella Karantzoulis, Ph.D., Clinical Neuropsychologist at the Barlow Center and spoke with Pamela’s nurse practitioner, who provided Pamela with comforting advice and a prescription for a sedative for Norma. The weeks that passed were brimming with tension as Pamela’s husband was unsupportive of the living situation. Again, Pamela reached out to Yaël who recommended she consult with a geriatric care manager, who provided Pamela with the names of nursing homes. However, these homes had long waiting lists.

Despondent, Pamela asked her Monsignor for help in placing her mother at a Catholic nursing home. As fate would have it, a few days passed and one morning Pamela received a call from a nursing home saying a bed had opened up and if she wanted the space, she would have to bring her mother in by 6:00 p.m. that evening. Plagued with guilt, confusion and self-reproach, Pamela decided this would be the best decision. Within hours, Norma was listed as a resident of the Catholic nursing home on Manhattan’s Upper East Side.

This decision marked the beginning of a new life for Pamela. As she says, “I found joy in my life... joy that I had lost sight of... my beautiful, healthy son, my loving husband, my wonderful friends. Placing my mother in a nursing home helped me to reclaim my life, which I feel I never had. As far back as I can remember, I was always taking care of my mother. Now, I am able to take care of my life.”

She adds, “I realized that I could not give my mother the care she needed while she lived with me. She required medical care that can only be found at a qualified nursing home. It was selfish of me to think that I could take care of mum. I was not aware, that as much as I loved her, I was not equipped to care for her, not anymore. Now I have peace of mind. For anyone who has experienced or continues to experience what I have been through, all I can say is that you may be hurting your parent more than helping him or her by having them live with you.”

Pamela’s story is unfortunately not uncommon. Caring for patients with Alzheimer’s disease and related dementia is perhaps the most difficult form of care-giving. Dr. Galvin adds, “Caregivers of Alzheimer’s patients experience stress, strain, grief and depression as a result of the burden they face. They often become more socially isolated and find that they have less time to attend to their own personal life and family. Caregivers are also at an increased risk for infection, hypertension and heart disease. It is critical that in their role as caregivers, they not only care for their loved ones, but care for themselves and be willing to ask for, receive and accept help from others.”

When asked how she got through these difficult years, Pamela says softly, “I prayed.” She also credits the Barlow team for giving her strength. As she puts it, “They were like family to me.” Now, Pamela has hope. Her mother is content and her days are filled with activities under the supervision of trained staff. For Pamela, the light that she has been longing to see has finally emerged. Darkness has turned to dawn.

Walking for a Cure

The Silberstein Alzheimer’s Institute was a major sponsor of the NYC Chapter’s Alzheimer’s Association Memory Walk, held at Riverside Park in Manhattan. This is the nation’s annual largest event to promote awareness of Alzheimer’s disease research, care, and support. Our team, “Aging with Excellence,” included 30 walkers and volunteers from various centers and programs within the Institute, including Alzheimer’s Disease Center, the Fisher Alzheimer’s Program, the Pearl Barlow Center for Memory Evaluation and Treatment, as well as the Nathan S. Kline Institute for Psychiatric Research (NRI). The Center for Dementia Research at NRI also participated in the Rockland County Memory Walk in Sparkill, NY. Monies from both Walks help support research and provide essential programs, services, support and education to people with Alzheimer’s disease as well as to their families and caregivers.
We hear a lot about translational research. Could you provide a clear definition?

Translational research is often referred to as “bench to bedside” which means translating scientific findings from the lab into practical or clinical application, i.e., the patient’s bedside. Think of it as a two-way loop between laboratory studies and clinical research (clinical trials) — between scientists finding novel therapies and physicians treating patients. Valuable knowledge from the laboratory is applied toward new tests in clinical trials, and findings derived from these clinical trials are taken back to the lab to be further investigated by basic science researchers. For translational research to be successful, collaboration among scientists and clinicians is a must.

Is it true that there are specific risk factors linked to Alzheimer’s disease?

Yes. Evidence suggests that there are certain risk factors that may increase or decrease one’s chances of developing Alzheimer’s. Some are modifiable and lifestyle-related, some not, for example genetics and age. Barlow Center clinicians cite the following as the top modifiable risk factors linked to Alzheimer’s: high blood pressure; smoking; unhealthy diet; lack of exercise; and diabetes. I should point out that a growing body of evidence reveals that there is a clear link between the heart and brain. People with high blood pressure and heart disease are at higher risk of developing vascular-related brain damage. Eating a nutritious diet, being physically active, engaging in social enjoyment, and being mentally stimulated can help people stay healthy at any age. New research suggests the possibility that these factors also might help to reduce the risk of cognitive decline and Alzheimer’s disease, particularly when adopted early in life as part of one’s lifestyle.