



David Hyde Pierce is a favorite among young and old!

A Night at Spamalot: Laughter Really Is the Best Medicine

“Isn’t it wonderful to be doing something for Alzheimer’s disease and be able to laugh at the same time?” asked actor and Broadway star David Hyde Pierce. Truer words have seldom been spoken.

David’s father and grandfather both suffered from AD and in the past year his involvement in and support for the Alzheimer’s Association, NYC Chapter, has been extraordinary. From his participation in Memory Walk to the lights of Broadway, he’s been using his “celebrity” to bring much-needed attention to AD – and on January 25th he brought his fellow cast-members from the smash-hit musical, *Spamalot*, to join the effort!

Donors, Chapter Board members and staff, friends and other supporters showed up in droves to attend a sold-out performance of the Broadway musical to benefit the Chapter. The evening’s festivities included a pre-show cocktail party at the Shubert Theater, the performance, and dinner with the cast at Carmine’s Restaurant. It was sponsored by the Women in Action committee, a *dynamic group of women who are raising public awareness about AD as well as funds to continue vital programs and services for the Alzheimer’s community in NYC. This event raised \$100,000.*

Academy Award winning actress Olympia Dukakis attended as a spe-

continued on page 7

“THE CAREGIVER SOIRÉE”

Honoring Caregivers

Through the generosity of Senior-Bridge, Inc., the Chapter was delighted to hold its 2nd Annual *Caregiver Soirée* on November 14th. Over 300 care-

continued on page 8

Acknowledging 100 Years of Alzheimer’s Disease

turn to page 11

Inside This Edition

President’s Message	2
From the Program Director	3
Telling Our Stories: The Sixth Annual Early Stage Memory Disorder Forum	4
Telling My Story: An Interview with Maureen Matthews	4
Dementia Home Care Graduation	5
Alzheimer’s Association Safe Return®	6
Alois Alzheimer - A Living Legend	9
Point/Counter Point	10
Reflections - Jim Lebenthal	11
Alzheimer’s in the News	12
Bookshelf	13
Junior Committee Update	13
Public Policy	14
Partnering With Your Doctor	15
Legal Guidance	16
Drug Update	NYCARE 1
Clinical Trials	NYCARE 2-5
En Español	En Español 1-4
Education Calendar	19
Caregivers’ Corner	22
Support Groups	23
Reaching Out to All New Yorkers	26
Volunteer Spotlight	27
Development Report	28
Lotos Club Event	28
Ways to Give	29
Tributes	30
HonorGift Tribute Cards	33
Know Your Charity	33
ALZNYC Jewelry Boutique	34

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president's message



Dear Friends,

Information. These days, we are all receiving more than we ever imagined – and the real task is figuring out what is accurate and truly useful. As I celebrate my two year anniversary at the NYC Chapter, I am more confident than ever that good, solid information and improving the way we communicate will help us build a smarter, more resilient, more cohesive Alzheimer's community.

Our dedicated professionals work hard to accomplish this. We have streamlined and improved the quality of information available on our web site – and through our focused media campaigns, we have raised awareness about Alzheimer's disease and Chapter programs and services.

Key among our accomplishments is the extraordinary evolution of our Newsletter into a substantive, entertaining, and compelling resource. Not content with this success, we are always looking to raise the bar, and in this issue, once again, we have added a new and informative feature. We thank Forest Pharmaceuticals, Inc., for generously underwriting this exciting Spring issue of our Newsletter.

In *Point/Counter Point*, we offer two opposing sides of an important issue facing our community. We propose to tap prominent experts in the field – researchers, scientist, doctors, social workers – to present both sides of a debate. We want you to assess the information, discuss the issue among your friends, family and Alzheimer professionals, and then make an informed decision.

In our first *Point/Counter Point*, two world renowned researchers – Mary Sano of the Mount Sinai School of Medicine and Marilyn Albert of Johns Hopkins University School of Medicine – square off to discuss the current debate on brain health. Next issue's column will deal with the important question of whether a person with Alzheimer's disease or a related dementia is better treated by a geriatrician or an internist.

In our Summer issue, we'll highlight a new "Ask Reva" column, where our Director of Clinical Services, Reva Hoffman, will answer "Frequently Asked Questions" from callers to our 24-hour Helpline.

One of our most popular new additions has been "Reflections." In recent issues we have featured interviews with actors David Hyde Pierce and Dominic Chianese. This month, we focus on the needs of caregivers in an interview with Wall Street icon, Jim Lebenthal, who speaks openly and with tenderness, about his role as his wife's caregiver.

I am extremely proud to let you know I was selected as the first-place winner of the prestigious *OTTY Community Builder Award* presented by Manhattan Media. While this award recognizes my efforts on behalf of the Alzheimer's community, it is an award I share with all of the dedicated professionals at the NYC Chapter and with each of you, who have made my job so rewarding over the past two years. I know we will continue to make progress!

And, finally, please, send me your thoughts about the newsletter and your ideas for future issues. Our goal is to make this, and everything we do, responsive to you – our clients, our friends and our supporters.

—Lou-Ellen Barkan
President & CEO



from the program director

Dear Readers,

The NYC Chapter has many roles: we educate, inform, support and assist persons with Alzheimer's and related disorders, their family caregivers and professional care providers. Our national organization is the world leader in dementia care and the largest private funder of research. We are the nation's leading advocate for our mission, bringing the voice of the person with dementia and their family to Washington, Albany and City Hall.

There is another kind of advocacy the NYC Chapter provides to help families ensure the best possible care for their relatives with dementia. Frequently, over the Helpline, in our support groups and at education meetings, we learn about situations where the caller needs an advocate to ensure good care. One caller asked us to intercede with his home care agency in order to obtain latex gloves for the family's home care worker. We referred him to the case manager and the nurse coordinator at the agency. If that was unsuccessful, we suggested he report this problem to the State Department of Health, which licenses home care agencies. Following his conversation with the agency, our caller received a satisfactory response.

The daughter of a nursing home resident called to report her mother had been injured several times by what she felt was neglect and unnecessary roughness in transferring her aged frail mother from bed to wheelchair. She had tried to speak with the nursing director, but did not succeed. We discussed how to best communicate her concerns in a constructive way to the nursing home staff and administration. Although it may not be a direct result of her advocacy, that nursing home now has a new director of nursing, and a new specialized person-centered care program for persons with dementia.

Daily we receive calls from the families of residents in adult homes, assisted living facilities and nursing homes – some with very serious complaints ranging from elderly demented residents being sent to the hospital without an escort and without notification to family members, issues of understaffing, (especially on weekends), occurrences of residents lying in their own feces for hours at a time, reports of lack of activities, poor medication management, observations of unclean environment, and incidents of residents wandering out of the facility. One daughter reported that, due to inadequate staffing, her elderly father was left in a shower chair, naked, wet, cold and shivering for over an hour, because there was only one attendant.

Many family caregivers are intimidated by the administration of these facilities, and are fearful of speaking out. The NYC Chapter is here to ensure there will never be a need to tolerate inadequate, neglectful and potentially seriously harmful care. The NYS Department of Health operates a hotline to report problems for residents of nursing homes, and other facilities they license – and we encourage families to register a complaint with the DOH. This can be done anonymously, if one is fearful of retaliation, but our experience shows that residents who have families that are active advocates get better care, because the institution knows that someone is watching out for the family member.

It is particularly important for the vulnerable population of persons with dementia, those who cannot speak for themselves, to have thoughtful, responsible parties looking out for

continued on page 18

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Telling Our Stories: The Sixth Annual Early Stage Memory Disorders Forum

Tuesday, April 25, 2006 has been chosen as the date for this year's early stage event: The Sixth Annual Early Stage Memory Disorders Forum. Formerly called the Annual Early Stage Alzheimer's Conference, it is felt that the new name more accurately reflects the target audience and the true nature of the day. It acknowledges that other related disorders, besides Alzheimer's disease, cause progressive memory problems. Additionally, referring to the day as a "forum" rather than the more scientific-sounding "conference," reflects its "friendlier," less formal tone.

The theme of this year's Forum is "Telling Our Stories: Living with Progressive Memory Loss." It will be highlighted by a dramatic presentation of personal accounts of the lived experience of dementia. The script consists of the words of those with Alzheimer's disease and related disorders, and the actors will be people with the diagnosis. The drama will be compiled by Maureen Matthews, and professionally staged and directed with the assistance of a group called "Artists for Alzheimer's."

Dr. Jeffrey Nichols, Vice President for Medical Services, Cabrini Eldercare Consortium, has agreed to conduct the medical session. Dr. Nichols will be discussing strategies to maintain health for the person with early stage memory disorders.

The Forum will feature nine workshop choices, as well as two additional workshops in Spanish. A special offering this year will be a two-part workshop entitled "Writing Your Story." Part A will be offered in the morning, and Part B in the afternoon. In keeping with the Forum theme, it will provide techniques for telling a personal story, or helping others tell theirs.

The all-day event will be held at The Graduate Center - CUNY, 365 Fifth Avenue (bet. 34th & 35th Streets), Manhattan, from 8:30am to 3:30pm. To register for the Forum, or for additional information, please call 212-983-6906 ext. 230, or visit our web site at www.alznyc.org. On-line registration is available.

TELLING MY STORY: An Interview with Maureen Matthews

Maureen Matthews, RN, Ph.D., is an adult mental health nurse, on whose research the plenary session for The Sixth Annual Early Stage Memory Disorders Forum is based. Maureen



has generously participated as a workshop leader in many of the past early stage events, and is the author/editor of the script "Telling Our Stories" that will be dramatized at this year's forum. She is interviewed here by Susan Goldfein, Program Coordinator.

Q: Could you share with us your professional background?

A: I have been a nurse for over 30 years. At first I worked primarily in medical settings, including two years in public health in the mountains of northeast Brazil. In graduate school I specialized in adult mental health nursing which led to opportunities to work with older adults. My interest in the experience of illness from the perspective of the person affected led to my pursuit of a research degree which I recently completed at New York University.

Q: How did your career in nursing lead you to a special interest in Alzheimer's disease?

A: Chance and a good fit with my personality led to my interest in AD. I was offered an opportunity to set up a Gero-psychiatric Unit at a nursing home when I finished graduate school. Those were the days when an older person with cognitive impairment was diagnosed with organic brain syndrome - OBS. Senility and disease were only beginning to be distinguished. Setting up the unit brought me into the world of brain disease and the individuals and families that were affected.

Q: What or who influenced your decision to use as your dissertation topic the personal stories of people with early stage memory disorders?

A: I have worked with adults with the diagnosis in many settings: home, outpatient clinic, assisted living, and nursing homes. I have been involved in evalua-

continued on page 5

Telling My Story...continued from page 4

tions, care-planning, and education of caregivers and professionals. During the 1980s we focused on the neuropathology of the disease. I assured caregivers that agitated, disruptive behavior was “the disease talking” and not the person they loved. This separation of the person from his/her actions contributed to the popular understanding of the person with AD reflected in phrases such as “a shell of the person they once were,” and “loss of self.” My understanding of the PERSON with AD or any other dementia-related illness began to change when a caregiver shared with me his wife’s journal. The journal revealed a woman who was acutely aware of her diagnosis and the changes it was causing in her life. While reading this journal I realized that this woman was reflecting upon her experience in an attempt to make sense of it. To assist this woman and her family through this difficult time, her voice needed to be included. Since that time, I have included in my clinical practice opportunities to listen not only to the caregivers but also to the persons afflicted. They speak of altered relationships and an altered sense of themselves. They speak of being demoralized by dependency and their desire to maintain their dignity. They describe fear. They also have a capacity for humor, often directed at themselves. I brought this awareness of the voice of the person with dementia to this study. I believe that dementia, like other chronic illnesses, forces a person to understand his/her life within a new context. Many hesitate to share their fears because of social stigma. Like cancer in the pre-hospice days, everyone knows it’s there but nobody wants to talk about it. My hope in this study was to get beyond the silence of dementia to the person who lives with it daily.

Q: How did you arrive at the decision to present your findings in dramatic form?

A: In my study I was asking people to tell me what it was like to live with dementia. They responded by telling me stories about themselves. Self-stories are the way in which people make sense of their experience in the presence of another. My challenge was to combine the first person communication of the self-narrative with my analysis and interpretation. I wanted the reader to hear what I heard, told in the words, body language and emotions, all of which are important dimensions of communication that risked being lost in the text alone. Dramatic form makes this possible.

Q: What did you learn from your experience?

A: I learned that everyone’s experience of living with dementia is told in the context of their unique life story. Life experiences, values, challenges, successes, failures, etc., shaped the impact of dementia in their lives. And while each context was unique, they shared similar experiences of living with the unknown. I also learned that a person’s story is a good way to “recruit” others to provide support and assistance. How can I get you to look at me and find me interesting enough to help me continue to grow as a person? The participants drew me in through their stories. Their narratives are effective tools of engagement which serves the person with dementia well.

Q: What message would you like the participants in this year’s Forum to come away with?

A: When a similar play was presented by women with metastatic breast cancer, a researcher who attended commented that during the play “everyone had cancer” because they were drawn into the experience by the actors. I hope something similar happens at the Forum. I hope that for a few minutes, everyone will have dementia.

Dementia Home Care Graduation 2005



What better way to end the year than with another graduation ceremony on December 8th, honoring 18 home care workers who successfully completed our Dementia Care Training Program. The graduates are employees of CABS Home Attendants Service in Brooklyn. The ceremony began with an opening prayer beautifully delivered by graduate Leutinna Bennons-Crooks. Family members, friends, and staff from CABS and our NYC Chapter listened as speeches about the training experience were given by Marcia Austin and Wendy Toppin, two of the graduates. Both stressed the importance of proper training for aides who are providing care for persons with dementia. To close the ceremony, the group treated their audience to a lively rendition of “Ain’t No Stoppin’ Us Now.” The afternoon ended with a joyful reception and many good wishes. Funding for the training was provided by a foundation that wishes to remain anonymous.

—Paulette Michaud, Manager of Education, Training & Early Stage Services

Driving and Safe Return

There has been an increase in missing person incidents involving persons with dementia who were driving.

- Mrs. S., 63 years old, drove to go shopping, and was reported missing when she did not return home. She was found deceased 11 days later after driving into a wooded area and attempting to find her way home by foot.
- Mr. K., age 82 and a Queens resident, was reported missing after driving to his daughter's nearby residence. He was found in Brooklyn 2 days later after being in an accident, and taken to the hospital with back and neck injuries, and dangerously elevated blood sugar levels. He told his family that he couldn't find his way home. He is now registered with the Alzheimer's Association Safe Return® program and will no longer drive. His family is receiving ongoing information and support from our Chapter.

Although often a difficult discussion, if the person you care for is still driving and has a diagnosis of AD or related dementia, plan time to talk about driving and safety. AD affects the complex skills that are required to drive safely: good perceptual abilities, quick reactions and the ability to make split second decisions. It is important to know that as the disease progresses, cognitive and motor skills decline, driving becomes more difficult and thus, more dangerous for them and others.

We live in a city with 24-hour transportation services. However, for many, driving symbolizes a sense of freedom, independence and convenience. Conversations about driving may be challenging. We offer the following:

Assess the person's ability to drive

- Have the person's driving ability tested in order to determine how well he/she sees, judges distance, and responds to traffic. Ask the person who administers the test to explain the results to you and the person with dementia.
- Look for signs of unsafe driving, such as forgetting how to locate familiar places, failing to observe traffic signs, making slow or poor decisions in traffic, driving at an inappropriate speed, or becoming angry or confused while driving.

Strongly discourage driving if the person with dementia cannot drive safely

- If possible, involve the person with dementia in the

safe return®

decision to stop driving.

- Explain your concerns about his or her unsafe driving, giving specific examples.
- Ask the person to stop driving voluntarily.
- Arrange for special transportation services available for older adults.
- Arrange for somebody else to drive.
- Reduce the person's need to drive. If they are used to driving to the pharmacy to pick up their prescriptions, arrange for delivery.

If a person insists on driving, take these steps as a last resort

- Decide on a designated driver and give that individual exclusive access to the car keys.
- Disable the car. Remove the distributor cap, the battery, or starter wire. Install a "kill wire" to prevent the car from starting unless the switch is thrown.
- Consider selling the car and use the money for other transportation. (ex. taxi cabs, car service)
- Write a letter directly to the Dept. of Motor Vehicles stating your concerns, and request that the person's license be revoked.

For more hints about helping somebody to stop driving, and the location of driving evaluation centers, please call our 24-hour Helpline at 800.272.3900.

People with AD will wander and become lost, walking or driving. Registration in Safe Return is FREE OF CHARGE to residents of the 5 boroughs, thanks to a grant from the Office of the Mayor and the City Council. For an application or to enroll, call 212.983.6906 ext. 205. For those already registered, we ask primary caregivers to call 1.888.572.8566 with updated contact information, or for product replacement requests.

—Elizabeth Santiago
Manager, Safe Return



David Hyde Pierce, Kate Mulgrew and Claudia Waite enjoying the festivities at Carmine's

Event Chair, Tami Schneider receives hugs from Simon Russell Beale and Olympia Dukakis



David does for us, including his work as Honorary Chair of Memory Walk 2005 in Octo-

ber where he led the Opening Ceremonies."

A Night at Spamalot...continued from page 1

cial guest, along with *Star Trek* alum Kate Mulgrew and international opera soprano Claudia Waite.

Spamalot, an adaptation of the much-loved 1975 film *Monty Python and the Holy Grail*, won 3 Tony Awards in 2005. Joining Mr. Pierce (who stars as "Sir Robin") were his exceptionally talented cast-mates Hank Azaria ("Sir Lancelot"), Christopher Sieber ("Sir Galahad"), Steve Rosen ("Sir Bedevere"), Lauren Kennedy ("The Lady of the Lake"), Michael McGrath ("Patsy"), and Simon Russell Beale ("King Arthur").

After the show, supporters, guests, cast members and crew headed off to partake in a feast fit for the king of England at the sensational *Carmine's*, where the stars mingled with guests, signed autographs and took photographs with fans.

A long-time supporter of the Alzheimer's Association nationwide, David spoke emotionally about his involvement and his admiration for NYC and our Chapter. "When I am with this group, I don't think of them as friends—we're family," he said at *Carmine's*. "And as for Lou-Ellen Barkan, she is such an inspiration," David added. "She always does more than you expect."

Our President & CEO, Lou-Ellen Barkan repaid the compliment by adding, "We hope David's work keeps him in NY – forever! I know everyone in this room tonight shares this sentiment. We are grateful for everything



Hank Azaria, "Sir Lancelot," joins us for dinner

Lou-Ellen also raised her glass for a toast to Tami Schneider for her unyielding leadership of the *Women in Action* Committee, saying, "The women of NYC: when you give us something to do, we're gonna get it done." Lou-Ellen also praised the cast of *Spamalot* for their incredible support and thanked Olympia Dukakis, Kate Mulgrew and Claudia Waite for attending as well. Lou-Ellen also singled out her staff for their work and exceptional dedication that made the evening a success.

We were extremely excited to see our own ALZNYC jewelry worn by many of the actors that night. The



Simon "King Arthur," shows off his "a reason to hope" cuff bracelet

Chapter gave each cast member and special guest silver bracelets — "a reason to hope" and "Forget-Me-Not," as a gift expressing our gratitude for their support. It was wonderful hearing cast members thanking us and exclaiming that everyone loves them. "King Arthur," Simon Russell Beale, and Olympia Dukakis both proudly wore the bracelets all night.

Women in Action, formerly known as the Women's Auxiliary, welcomes all who would like to lend their support in raising funds and awareness, currently with 45 active members and growing! Future *Women in Action* events will include breakfasts, luncheons and teas covering a variety of topics related to AD, along with social and cultural experiences.

If you are interested in joining *Women in Action*, please contact Amanda Levine, Director of Volunteer Leadership and Development, at alevine@alzny.org or 212-983-6906, ext. 241.



Charles & Mary Rowland with friend Pauline Hobson enjoying The Soirée

Soirée...continued from page 1

givers, their friends and relatives attended to celebrate National Alzheimer's Disease and National Caregivers Month at AuBar, a unique music and entertainment venue in NYC.

It was a wonderful and eventful afternoon. Jim Lebenthal, our special guest, brought wit and humor to the day with stories about his life as a caregiver and a municipal bonds salesman from his soon to be released book, "Confessions of a Municipal Bonds Salesman." Jules Helms of Stepping Out Studios led a vigorous dance lesson that got many caregivers on their feet and moving. We were swept away by the inspiring songs Barbara Lowin chose to sing as a finale to *The Soirée*.



Barbara Lowin wows the crowd

Alissa Pizzutiello, a leader of the Early Stage Alzheimer's Program at the Samuel FieldYM/YWHA in Little Neck, Queens, described *The Soirée* best, "This is fabulous. It gives us a sense of normalcy which seems so distant sometimes." Licet Valois Gonzalez echoed the feeling as she watched the members and relatives of her support group from the Elmhurst Senior Center dance to the jazz of the Ron Sunshine Full Swing Band, "This is what caregivers miss."

It was for these reasons the Chapter's Support Group Program created the *Caregiver Soirée*.

Indeed, having fun is "no trivial pursuit" according to Cindy Aron, PhD, in her July 1999 article in Psychology Today. "In fact," she wrote, "it's crucial to our mental



Many thanks to our friends at SeniorBridge, Inc.



THE CAREGIVER SOIRÉE



The Soirée in full swing

health and happiness it recharges us. It restores our optimism. It changes our perspective. It renews our ability to accomplish the work of the world."

At the 2nd Annual *Caregiver Soirée*, in addition to connecting to people we already knew, meeting new people, learning new dances, listening to jokes, songs and stories, if Dr. Aron is correct, we "renewed our neuronal connections" which could help us to adapt to new situations with more flexibility in the future; every caregiver's wish.

Special thanks to the *Caregiver Soirée* committee and hosts Nick Newcombe, Claudia Fine, Judy Adams, Bonnie Goodman, Judith Scher, Elana Sinsabaugh, Susan Caccoppolo, Ken Onaitis, Lorraine Ruggieri, Rita Golub, June Aaronson, Lori Rubin, Helene Ebenstein, Mary Hume, Matt Kudish, Cathy Warburton, Mary Hume, Ellen Sarokin, Elizabeth Santiago, Jasson Salganik, Susan Sugarman and Barbara London.

—Wendy Panken
Manager, Support Groups

Visit our Photo Gallery at www.alznyc.org to view the entire *Caregiver Soirée* album.



Above: The Caregiver Soirée Committee

Right: Lou-Ellen Barkan, Jim Lebenthal and board director Sunnie Kenowski Irving



Alois Alzheimer – A Living Legacy

One hundred years ago in Munich, Germany, the burly, gregarious Dr. Alois Alzheimer set down his half-smoked cigar, removed his pince-nez, leaned into his state-of-the-art Zeiss microscope and peered downward.

It would be difficult to imagine the precise brew of emotions he must have experienced at that moment. Not only was he the first person to learn about and witness “plaques” and “tangles,” the abnormal, insidious protein fragments destroying individual brain cells in the catastrophic process that we now call Alzheimer’s disease. Not only was this a breathtaking medical discovery that had implications for all of psychiatry and neurology. It was also a highly personal revelation: Alzheimer had known and personally cared for the patient whose autopsied brain lay sectioned and stained in his microscope. Five years earlier, he himself had admitted her into his hospital in Frankfurt.

This story of the 19th Century German neurologist and his patient, Auguste D., comes to us from a time and place far removed from our own, and probably feels musty to anyone following the molecular genetics of today. But it is still shockingly relevant to us all. For, in Dr. Alzheimer’s discovery of the disease that came to bear his name, we can also foretell the story of that disease’s cure.

Alois Alzheimer’s discovery was not one of chance. Far from it. This was a man with a bottomless well of curiosity who literally stayed up nights worrying about -- and investigating -- things he didn’t understand. Why would a middle-aged woman like Auguste D. (she was 51 when first admitted to the hospital) exhibit classic symptoms of *senile* dementia? Doctors were very familiar with this vexing component of old age. But 51 was decidedly pre-old. The more time he spent with his helpless patient, and the more he studied brain tissue in his lab, the more he became convinced that there must be a very particular pathology associated with Auguste D.’s illness -- and that with the right tools, this disease could be made visible.

Such was not the orthodoxy at the time, to say the least. Neurologists and psychiatrists from this era did not believe that brain illnesses manifested themselves on a cellular level, but rather were connected to an imbalance of fluid or a drain in the brain’s “nerve force.” Nor had they seen any evidence to the contrary. No scientist had ever presented solid proof that specific changes in brain cells could be correlated to any specific brain illness.

Alois Alzheimer changed all that. It was his first-hand

observations of plaques and tangles, and his ability to connect them to the specific illness of Auguste D., that put brain science on a whole new path.

But first he had to get through his peers -- and therein lies Dr. Alzheimer’s contemporary relevance. For when he took this startling new information to the next important scientific conference, was he given a hero’s reception? No. He was laughed right off the stage. *Changes in brain cells connected to a mental illness! The absurdity!*

Science, in its truest and best form, is a curious blend of rigidity and openness. Good scientists must be extremely skeptical about anything not yet proven to be true, and dedicated to constant scrutiny of what they already “know.” Most often, advances in scientific knowledge come at a painfully slow pace and add to recorded knowledge only in small increments. At the same time, though, scientists must be open to startling new truths -- information and perspective that could turn their understanding upside down.

That’s the idea, at least. The reality is that it is human to get stuck in certain ways of thinking, and to disregard ideas that stray too far from the norm. Very often, when a big new truth is discovered, it gets laughed at; it goes unsupported and unfunded.

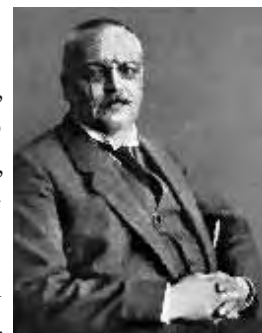
Alois Alzheimer had the courage of his convictions and the funding to pursue his ideas. Do we? Some of the most important advances in research over the last decade have come from mavericks, including Allen Roses and Dale Schenk, who were initially laughed at or ignored. The Alzheimer’s Association and other institutions funding research need to pay special attention to ideas outside of conventional wisdom.

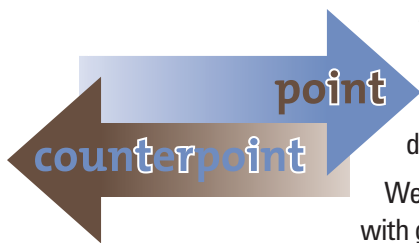
Further, it is the responsibility of *everyone* reading this newsletter to insure that today’s scientists have the funding that they need to do their best work. Incredibly, Alzheimer’s research still does not get nearly the federal dollars it deserves. We cannot afford -- emotionally, socially, economically -- to live with this disease for another generation.

—David Shenk



David Shenk is author of “The Forgetting,” which inspired the PBS film of the same name. He lectures frequently on the history, biology and social urgency of Alzheimer’s.





Welcome to our inaugural “Point/Counterpoint” column. Many areas of dementia care and research are unclear, with often two or more sides to an issue. Our goal is to help you become a better educated consumer; more knowledgeable so that you can make decisions based on a foundation of information, not innuendo or propaganda.

We will address the issue of maintaining brain health, and “preventing” Alzheimer’s disease, with guest columnists, Marilyn S. Albert, Ph.D., of Johns Hopkins Medical School, former chair of the Alzheimer’s Association’s National Medical and Science Council, and Mary Sano, Ph.D., Director of the Alzheimer’s Disease Research Center at Mount Sinai Medical School.

Please let us know what you think about this column by writing to Jed Levine, Director of Programs, Alzheimer’s Association, NYC Chapter, 360 Lexington Avenue – 5th Fl., NY, NY 10017 or by e-mail at jlevine@alzny.org.

Keep Your Brain Fit

There is increasing interest in whether changes in relatively simple daily activities can influence brain fitness as one gets older. Fortunately, there has also been some research in this area to guide recommendations.

The first set of recommendations grow out of a study begun many years ago, with funding from the MacArthur Foundation Research Network on Successful Aging. This research network followed over 1,000 community-dwelling individuals, aged 70–80, for almost 10 years. Only people who were doing fairly well, both mentally and physically, were asked to participate. Large amounts of biomedical and psychosocial data were obtained at baseline and at each follow-up evaluation (spaced about 3 years apart). The goal of the study was to determine which measures obtained at baseline predicted who would maintain mental ability over time.

Four factors, working in combination, turned out to be predictors of who would have higher cognitive test scores on follow-up: (1) higher levels of education, (2) higher levels of physical activity, (3) better lung function, and (4) greater feelings of ‘self-efficacy’. When all four factors were present, there was a much greater likelihood that an individual would function well on follow-up. Subsequent research, in both animals and humans, has suggested why these factors might be important and how they might operate to keep the brain fit.

It is thought that the more education one has, the more likely it is that one will be mentally active throughout life, and that ongoing mental activity helps strengthen connections between nerve cells in the brain. This in turn enables the brain to function more

continued on page 21

Keep Your Mind Open

It makes sense to hope an ounce of prevention is available to save us from needing a pound of cure. However, sometimes the best knowledge humbles us to realize there is no answer. Preventing Alzheimer’s disease and cognitive loss falls into this category. While we know several factors that are associated with Alzheimer’s disease, it is not so easy to assume they are causative. For example, the most well established factor associated with Alzheimer disease is age. Our increasing life expectancy along with the growing technological demands of daily living increase the awareness of dementia. It has been estimated that 1 in 5 people will be affected by their own cognitive disability or will be caring for someone with cognitive loss or dementia.

We must recognize that an association with an increased or decreased risk of dementia can be misleading. For example, epidemiologic studies have suggested that estrogen use may be associated with a reduction in risk of dementia and better cognitive function but very careful studies designed to examine cause, not just association, leads us to a different conclusion.

Higher education may be protective but it may also be that cognitive deficits and dementia are less detectable among people with more education. In fact, this was the original model of cognitive reserve, which implied that because a person had more experience with cognitive tasks, symptoms did not appear until they had more brain pathology.

The latest axiom is that maintaining a healthy heart also helps maintain a healthy brain. Unfortunately there is very little evidence to support this. While some observational studies have demonstrated an association between heart disease risk factors and dementia, well controlled clinical trials of drugs that have demonstrated

continued on page 21

reflections

Lou-Ellen Barkan: Jim, thank you for joining us today. Our readers are interested in what led to your interest in Alzheimer's disease.

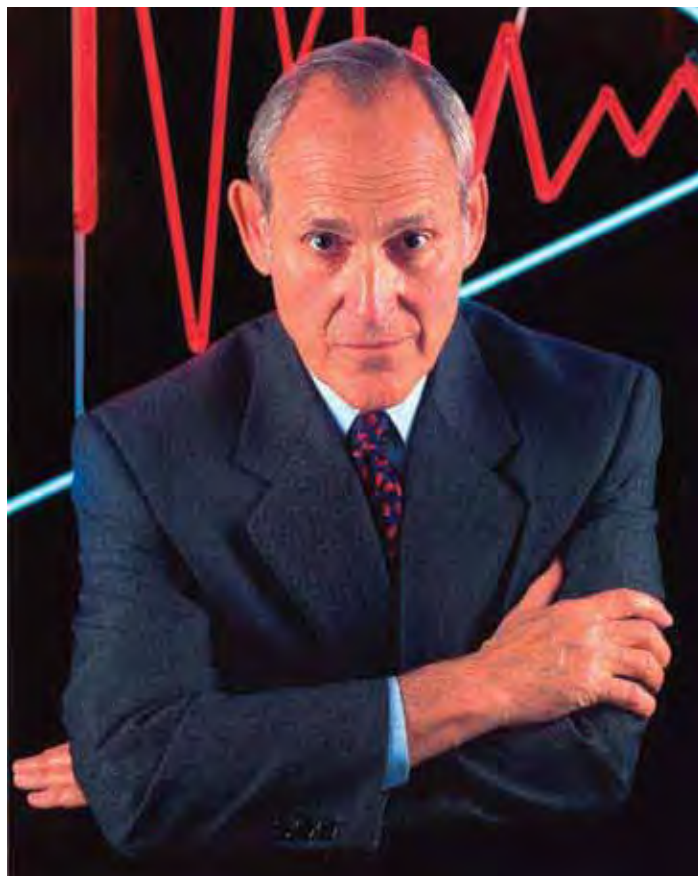
Jim Lebenthal: In John Irving's book, *The Cider House Rules*, there's a story of a cantankerous old man and with a wonderful whammy Irving reveals it was Alzheimer's. All of a sudden, the man's behavior becomes understandable. At the same time, there was a kiosk poster with a picture of an older man, standing, looking out with an unpleasant look on his face. The caption was, "It's not you, it's Alzheimer's." That's when my sensitivity began, but it was unrelated to my personal life until Jackie, my wife, who had been a vibrant live-wire began acting stubborn, irascible. I assumed that it was me, not Alzheimer's.

One night, we had a fight over a can of crabmeat. I came home late and helped myself to a can. She seized it and we had a violent argument. Two, three months later -- you lose the sense of time in clocking the progress of this disease -- I realized that the problem was her inability to explain, "Jim, that's for dinner tomorrow night." That can stayed in the refrigerator for eternity and when I finally opened it, it stank to high heaven. It was such a mockery of the situation.

That was the beginning of my realization, but there were other incidents as she was more obviously forgetting things. She left her purse on the train several times. I have videos of Jackie standing in the garden keeping an eye on it, watching it, watching the grass grow. You reconstruct these signs afterwards. But by the end, these incidents are exhibit A, B and C, and they emerge from your memory as if a lawyer is presenting a case. "Ah-ha! That was the first sign."

One night I received a call from Jackie's hairdresser. She asked, "Has your wife come home?" She hadn't. She said that Jackie seemed not "altogether." That was the final wake up call. I called the police to report her missing. As I waited with the policeman, the doorman called to say, "Your wife's downstairs. She has no money." The next day I called your "Safe Return" program.

During this time, I was taping videos for my "Crazy About New York" web site and happened to have a shot of Jackie from behind sitting with her face to the bay. Her hair is blowing in the wind, the tall grass around her



is waving, but she is absolutely still. That is the image I have of her departure.

LEB: And the next step -- how did the assessment go?

JL: I surrendered to the neurological process. I tried to make the monthly check-ups fun. "Honey, on the quiz, name-four-four-legged-animals, they're going to challenge you when you say kangaroo. Hold your ground." I found the visits routine, an inexorable descent into ritual, but went along with the inevitable. One time, after maybe seven, eight visits, the doctor asked her, "What do you think of this process?" And she said, "Bullshit." And that was, well, famous last words. I said, "That's the first intelligent thing you've said, Honey." Jackie was never formally diagnosed as having Alzheimer's. Once on leaving the doctor's office, I heard him use the word Alzheimer's to the receptionist." I said, "Doctor, that's the first time you've given us a label." And he said, "You can use it." That was as close as we got.

LEB: Was that the only clarity you received? How did you handle that confirmation?

JL: During this time, I developed the "Confessions of a Municipal Bond Salesman," both as a one-man show

continued on page 17

Study Bolsters Evidence for Memantine

A six-month extension to a large clinical trial offers further evidence that memantine (Namenda) may help individuals with advanced AD, according to a report in the January *Archives of Neurology*. Results showed that participants who received the placebo in the original six-month trial and switched to memantine in the extension declined more slowly than they had on placebo in assessments of memory, daily activities and overall function. Those who stayed on memantine throughout maintained their slower rate of decline seen in the first trial.

“This new data increases our confidence that the effect we’re seeing is real and seems to continue for at least a year,” says William H. Thies, Alzheimer’s Association vice president, medical and scientific affairs. “While the long-term solution to Alzheimer’s clearly lies in prevention and in drugs that stop the progression of the disease, it’s good to know we’re on solid footing with what we have to offer now.”

Data from the original trial were first reported in July 2000 in Washington, D.C., at the Alzheimer’s Association World Alzheimer Congress and later published in the April 3, 2003, *New England Journal of Medicine*.

Diabetes Drug Avandia May Help Treat Alzheimer’s Disease

Dec. 7 (Bloomberg) -- For 14 years, neurologist Allen Roses has argued that a gene discovery he made about Alzheimer’s disease would lead to new treatments for the mind-robbing illness. His prediction may finally be coming true.

Roses, a research executive at GlaxoSmithKline Plc, provided evidence yesterday that the company’s best-selling diabetes pill Avandia may slow the effects of AD. At a science meeting in San Diego, he presented a 500-patient study showing Avandia enhanced memory when compared with a placebo.

The study supports a hypothesis that the disease, which affects 4.5 million Americans, is caused by some of the

alzheimer's in the NEWS

same biological malfunctions that are involved in diabetes. The Glaxo researchers found that only people with a particular gene linked to a protein that transports cholesterol through the blood responded to the treatment.

Obesity, Alzheimer’s Linked

Jan 1, 2006 PHILADELPHIA (*myDNA News*)

If heart disease and diabetes aren’t bad enough, now comes another reason to watch your weight. According to a new study, packing on too many pounds can increase the risk of developing Alzheimer’s disease.

A team led by researchers at the Farber Institute for Neurosciences at Thomas Jefferson University in Philadelphia and Edith Cowan University in Joondalup, Western Australia, has shown that being extremely overweight or obese increases the likelihood of developing AD. They found a strong correlation between body mass index and high levels of beta-amyloid, the sticky protein substance that builds up in the Alzheimer’s brain and is thought to play a major role in destroying nerve cells and in cognitive and behavioral problems associated with the disease.

“We looked at the levels of beta-amyloid and found a relationship between obesity and circulating amyloid,” said Sam E. Gandy, M.D., Ph.D., director of the Farber Institute for Neurosciences. “That’s almost certainly why the risk for Alzheimer’s is increased.”

“Heightened levels of amyloid in the blood vessels and the brain indicate the start of the Alzheimer’s process,” Gandy said. The scientists reported their findings in this month’s *Journal of Alzheimer’s Disease*.

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To read the above articles in their entirety, visit www.alznyc.org/news.

**Introducing our updated 2006 Alzheimer’s Association,
NYC Chapter “Search for Services”
resource database at www.alznyc.org**

JC Hopes To Make 4th Gala Its Best Yet

The Junior Committee, led by gala co-chairs Christina Shepard and Meghann McKale, is hard at work on its Fourth Annual Spring Gala. This event is a vital part of the fundraising that allows the JC to support Chapter and research initiatives.

For the first time, the event will be held on a weeknight—as are many major charity benefits in the New York metro area—and call for “festive attire,” instead of the traditional black tie. The venue is the Lower East Side’s trendy BLVD, recently featured on *The Apprentice* as well as *Law and Order*.

Corporate sponsorship committee chairman Drew Skelton and his team are hard at work on nailing a corporate sponsor. The Junior Committee is also pursuing appointment of an honorary chairperson with not only name recognition, but a connection to Alzheimer’s disease. Never

before has the JC taken its planning for the gala to such an intense level, and the night promises to be a memorable one!

The event will be held 8 p.m. Thursday, April 27, at BLVD (199 Bowery at Spring St.). Tickets start at \$125. Visit www.alznycjuniorcommittee.org to purchase tickets. For more information, please contact Christy Johnson, chapter relations chairwoman, at christy_johnson@post.com.

In other news, the Junior Committee was pleased to learn recently that the Chapter Special Assistance Fund it is supporting this year has helped nine area AD families in need. Monies have been awarded for respite care and a desperately needed air conditioner, among other things. A successful 2006 gala will ensure that the committee can continue to help further the NYC Chapter’s mission.

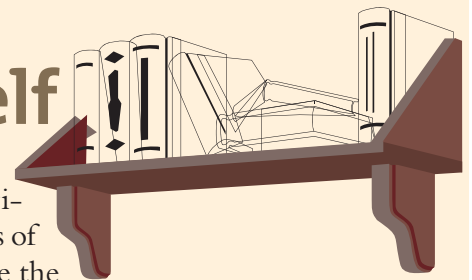
Patricia Garbarini’s set of seasonal books for persons with AD

Millions of Americans diagnosed with Alzheimer’s disease and other dementias, and their caregivers, face multiple challenges. As the ability to function independently deteriorates and as memory declines, one of the most poignant and frequent questions asked by caregivers is, “What can my relative and I do together?”

Patricia Garbarini, after devotedly caring for her father, has produced a set of lovely books that help answer that question. By combining language that is simple and clear, without being either childish or demeaning, and photographs that are evocative and beautiful in their own right, she has given both caregivers and people with dementia books that are certain to provide them with moments of respite from the daily demands of the disease.

Spring in the Park, Summer by the Water, Autumn in the Country, and Winter Fun can be shared by two people or enjoyed alone. For a person with dementia, the pictures may momentarily jog a memory like the smell of lilacs, the taste of a crisp apple, the beauty of a summer sunset or the fun of riding on a sled, reawak-

bookshelf



ening a lost experience. These images of life’s pleasures have the potential to stimulate conversation by rekindling feelings. The intangible pleasure of an artistic or aesthetic experience is not lost to persons with AD, regardless of whether or not the experience is later remembered.

We know that there is innate value for all of us in creating and sharing the simple beauty of the world around us— a world captured in these books. Art and beauty help balance the scales, heal some of the hurt, and enrich the fading spirit. We can all be grateful to the author for contributing these wonderful gifts to those who live in the world of dementia.

You can purchase the series (\$60) or individual seasons (\$15) — visit ALZNYC Bookstore at www.alznyc.org or call 212-983-6906 ext. 217. A portion of the sales will be donated to the Chapter.

—Reviewed by Jed Levine



PUBLIC POLICY UPDATE: Federal and State Alzheimer's Advocacy

Federal Update

The reconciliation process involving the Senate and House tax cuts and spending bills concluded during the week before Christmas. The budget passed by the House prior to Thanksgiving had called for \$50 billion in mandatory program spending cuts over five years. The spending cuts included changes to Medicaid of deep concern to advocates for Medicaid health care and long term care. The House budget included specific limits on asset transfers to establish Medicaid long term care eligibility. The Senate budget was not as severe. As such, the merging of the Senate and House versions and the final Congressional vote held great importance for persons in need of Medicaid long term care.

What emerged from the conferencing before the holidays, despite intense advocacy opposition, tilted in favor of the House more restrictive approach. The conference agreement calling for \$41 billion in budget cuts was then approved by the House. The agreement held that Medicaid would not cover nursing home long term care for persons with home equity of more than \$500,000 although a state could choose to set the ceiling up to \$750,000. In addition, the look back period for transfers of assets was extended from three to five years. The start date of the penalty period for transfers during the look back period was changed, thereby delaying the start of a penalty period and Medicaid coverage for nursing home care. (For a fuller discussion of the transfer of assets changes, see page 16 by elder law attorney, Bernard Krooks.)

With a tie broken by the Vice President, the budget reconciliation passed the Senate on December 21st. A point of order, however, by the Ranking Democrat on the Budget Committee, Senator Conrad (ND), was sustained, and the agreement was sent back to the House because of minimal changes. The final passage of the tax cuts and spending bills concluded on Feb. 1st with the House passage of the budget reconciliation calling for \$39.5 billion in cuts, 216 to 214 votes.

National Institutes of Health (NIH) research funding was also delayed. A House/Senate Conference Committee had been appointed to resolve their differences. The Committee reached an agreement calling for the lowest increase in three decades and much less than the Senate's original recommendation of a 3.7% increase. On November 17th, the House rejected the Commit-

tee agreement, in part attributed to House member concerns that the NIH funding was too low. When the Committee met again in mid-December, no additional funds were added for NIH. Subsequently, the House and Senate passed the conference report and the exact amount of AD research funding is a slight reduction from current funding.

As expected, the Medicare Part D prescription drug benefit implementation has remained of deep concern and complexity to all eligible persons. This article can't possibly address the myriad of concerns and complexities that have arisen across all incomes. The advocacy organizations with particular Medicare expertise reported overwhelming numbers of requests for help in December. There are problems in understanding the benefit itself, the different plans available, and the drug formularies involved, as well as basically ascertaining one's particular status with regard to enrolling in Part D.

There are major difficulties for the tens of thousands of persons with AD in NYC who are dually eligible for Medicare and Medicaid as they have been automatically enrolled in plans. Many dually eligible who do not understand the enrollment process, may not even know they have been auto enrolled, and in what plan, prior to going to a pharmacy to refill their prescriptions.

State Update

Governor Pataki presented his final Executive Budget on January 17th. The Executive Budget calls for actions to limit and delay access to Medicaid eligibility for long term care that would have dire consequences for persons with AD, their families and other caregivers. The governor will seek to: establish an asset transfer penalty period for non-institutional long term care including the home care/personal care program; extend the look back period for transfers of assets from three to five years and apply it to non-institutional long term care services; and change the starting date of the transfer penalty period for Medicaid from the date the month following the asset transfer to the month the individual begins to access services. The governor also proposes a major initiative to combat Medicaid fraud.

It is expected that the State Department of Health (SDOH) will continue to work on the NYS Long

continued on page 24

Partnering With Your Doctor

Part II in a Series: Steps to Improve the Doctor Visits for the Person with Alzheimer's Disease

Research shows that:

- People who plan ahead for a doctor visit get more of their questions answered.
- They feel better about their care than those that do not plan ahead.
- Even though people who plan ahead get more out of the visit, they do not take up any more of their doctor's time than do people who don't plan ahead.
- They simply use the time they have better.

The first step in planning for the visit is to keep a care log. A care log is like a diary; it looks like a form. Use a care log to keep track of health changes.

Write in the care log:

- Changes in memory ability
- Drastic mood changes
- Unusual behavior
- Health related changes (to sleep, appetite, skin, hair...)
- Health complaints of the patient

Ask yourself: what does the doctor need to know?

Include: who, what, when, where, why.

Use the care log to keep track of things that happen between doctor visits.

Sample Care Log:

Name: <i>David Smith</i>		
Date	Time	Changes in Health/Mood/Memory/Behavior
<i>1/05/06</i>	<i>1:15 p.m.</i>	<i>David fell asleep in his chair while watching TV. When I tried to wake him after an hour, he became angry and pushed me away. He slept for 3 hours.</i>
<i>1//06/06</i>	<i>2:20 a.m.</i>	<i>David had a hard time sleeping tonight. He was pacing across the room for 2 hours. When I tried to get him to go back to bed, he started crying and seemed angry.</i>
<i>1/11/06</i>	<i>3:15 p.m.</i>	<i>David and I went to the mall today to walk and get some exercise. He seemed very irritable and tired. He hasn't been sleeping well all week.</i>
<i>1/14/06</i>	<i>2:30 p.m.</i>	<i>David and I went to the mall again for walking. He seemed very confused and kept asking where we were. I stopped to get us a cup of coffee and when I turned around, he had disappeared. It took me an hour to find him. He was very anxious and confused when I found him.</i>

How many of you have been asked by your doctor, "When did this symptom start?"

How many of you could remember the exact date?

Some of the benefits of the care log are:

- You don't have to worry about remembering all of the information during the doctor appointment.
- The care log can report things to the doctor that may be difficult for you to talk about in person.

- All care partners can be aware of changes in the patient.
- The care log can help reduce your stress
- The doctor receives detailed information to help in deciding on a treatment.

Before a visit to the doctor, make copies of the log and fax or mail it to the doctor, or give it to the doctor at the time of the visit.

Legal Guidance

Congress Passes Major Medicaid Legislation

Planning for your and your family's future has always been important, but it has never been more important than now. These issues are taking on a special urgency now that Congress has passed (and the President has signed into law) the Deficit Reduction Act of 2005 (DRA). The DRA has made substantial changes to the Medicaid rules that will make it much more difficult for seniors and those with disabilities to access much-needed long-term health care.

The DRA contains three major changes to Medicaid eligibility rules, along with many other significant changes to existing Federal Medicaid laws. First, the look-back period has been increased from 36-months to 60-months for all transfers. Transfers made outside the look-back period need not be disclosed to Medicaid. However, transfers made within the look-back period must be documented and explained to Medicaid. Under prior law, outright transfers were subject to a 36-month look-back period and transfers to or from certain trusts were subject to a 60-month look-back period. This change will require record-keeping that is far beyond normal practices, especially for victims of Alzheimer's disease or dementia.

Second, the start of the penalty period for someone who has transferred assets does not commence until the date that individual applies for Medicaid and is receiving institutional level care (i.e., in a nursing home or pursuant to a waived home care program) and whose application for Medicaid would be approved but for the imposition of a penalty period at that time. Thus, the individual must be otherwise eligible (i.e., have less than \$4,150 in non-exempt resources at that time). Under prior law, the penalty period for institutional Medicaid commenced on the month after the transfer is made. Under the new Medicaid law, the penalty period may not commence until five years after the assets have been transferred if that is when the person who made the gift is in a nursing home and applies for Medicaid.

By way of example, if someone transferred \$15,000 to his child prior to the date of enactment, he would incur a two-month penalty which would begin in the month after the month in which the transfer occurred. Under the new law, the penalty period on that same \$15,000 gift does not begin until the individual is in a nursing home, is receiving a level of care in any institution equiva-

lent to that of nursing facility services, or is receiving home or community based services furnished pursuant to a Medicaid waived program and that individual has applied for Medicaid and is otherwise eligible. Thus, if the gift was made in 2006 and the individual went into a nursing home in 2010 and was otherwise eligible and applied for Medicaid, the two-month penalty would not begin until 2010. The individual would not be eligible for Medicaid for two months and would not have any funds to pay for his care during that period. Fortunately, the rules for home care have not changed. You may still transfer assets and not incur a Medicaid penalty so long as you are applying for a non-waivered home care program. (Please note that Governor Pataki's recently released Budget Bill seeks to change this rule in New York).

Third, the equity in a Medicaid applicant's otherwise exempt home is countable to the extent it exceeds \$500,000. The DRA gives states the option of increasing this \$500,000 cap to \$750,000. The home equity cap amounts will be indexed for inflation beginning in 2011. The home equity cap does not apply to an individual whose spouse, child under twenty-one, blind or disabled is living in the home. Without proper planning, seniors will be forced to sell their homes or take out reverse mortgages in order to receive long-term care. Under prior law, a home was exempt regardless of value, if certain conditions are met. Unfortunately, even if the home is exempt it may still be subject to estate recovery if proper planning is not implemented.

The effective date for most of the provisions of the DRA is the date of enactment (the date the President signed the bill). However, in order for Federal Medicaid

continued on page 20



Bernard A. Krooks is a founding partner of the law firm Littman Krooks LLP, with offices in NYC and White Plains. Mr. Krooks is a past President of the National Academy of Elder Law Attorneys (NAELA), President of the NY Chapter of NAELA, and past Chair of the Elder Law Section of the NYS Bar Association.

Reflections...continued from page 11

and a book. I also had the videos I was making and “CrazyAboutNewYork.com” web site -- and I decided that nothing was going to stand in my way of doing those two things.

LEB: So they were a diversion for you?

JL: They weren't the diversion. My life was the diversion. Lebenthal & Company, the great success with the bonds, was a diversion. This was getting back to what I should have done for forty years. What we're dealing with here is what most caregivers will not allow themselves, their me-ness. But I had no guilt - just, “Darling, you didn't marry a bond salesman. I gotta let the artist out and make up for the past forty years.”

The significant event was that Lebenthal & Company was sold. All of a sudden, there was money and it was going to go into whatever it took to make Jackie comfortable and give me the chance to do long overdue things.

I had a very early creative career as a Time-Life correspondent and a producer for Walt Disney. Then I abandoned all of that and was in the bond business for forty years. So here I was the ideal spouse, loving, understanding...

LEB: Generous.

JL: Generous to a fault - to me! But getting my own life back on track put taking care of Jackie into perspective. Like we used to joke when we were first married with children, “Can a man have a job and a family?”

LEB: You know we often tell caregivers that in order to take care of others, you need to take care of yourself - not just physically, but emotionally.

JL: Absolutely. The caregiver must be nurtured. Until science finds a cure or a treatment, here's to the caregiver.

LEB: The Chapter serves two populations - the person with dementia and the caregiver. We give them equal weight. How did you make some of the important decisions about Jackie's care?

JL: I hired a daytime caregiver, Maria, who bossed me around and treated me like an absolute dummy. She would send me out for diapers with buttons, not the Velcro, and I'd always get it wrong. But she was a trained nurse and marvelous with Jackie. I realized this is fantastic and played along - as Dagwood Bumstead. Jackie and Maria went to visit Maria's family in

Costa Rica, where Maria was born, and it was heaven. But when they came back, after a month, Jackie was extremely agitated, slumping out of her chair to the floor. When her reaction to me turned hostile, it was time to remember, “It's not you, Jim. It's Alzheimer's.”

LEB: You had learned not to take it personally.

JL: I knew that we were dealing with the disease. I asked Maria, “Why don't you take Jackie back to Costa Rica for another visit?” “We can't,” Maria said. The house belonged to her daughter. It was tied up in a divorce and had to be sold. I used my resources, took it off the market and back they went to Costa Rica and Casa Lebenthal. Maria has a large family. If Jackie has to be lifted, driven down to the mall for an ice cream soda, they come and help. This is a house that is dedicated to Jackie's well-being. When I visit and try to be of some kind of help, it's shoo! Shoo! Out of the way! I love visiting. I get more work done in the solarium than I do at the office.

LEB: How has the geographical split affected your children?

JL: My son Jimmy wants Jackie home for her final years, but I explained that “Jackie is not in Costa Rica to die, she's there to live.”

LEB: So your choice is between keeping a loved one at home, where family may be next door, or a life of contentment faraway as she's living it now.

JL: Costa Rica is not banishment. And it's a lot closer psychologically and emotionally than a nursing home just around the corner. By the way, I don't kid myself about visiting. Proximity has nothing to do with it. Especially since the reasons to visit are clouded by the one question that comes up all the time with Alzheimer's: “Does she recognize you?” And it's the wrong question. The question should be, “Do you recognize her?” I give my kids the speech: You don't visit Mommy to get a reaction and be entertained. You go to show the world, Maria and her family, that you care.

LEB: To let the caregiver know that you have not abandoned their patient.

JL: And yet I don't ask my kids to visit if it means abandoning the image they have of their mother. I absolutely respect Claudia, Jimmy and Alexandra for their individual decisions on how they want to remember Jackie.

LEB: We always say that each family, each individual has to do what is right for them. Some family members can handle the obligation, but if you can't, to

continued on page 25

N.Y.C.A.R.E.

The New York Consortium for Alzheimer Research and Education (N.Y.C.A.R.E.) is the joint effort of the New York City Chapter of the Alzheimer's Association and the Education and Information Cores of the Alzheimer's Centers at Columbia University – College of Physicians and Surgeons, Mount Sinai Medical Center, and New York University School of Medicine, funded by the National Institute on Aging.

Drug Update

In the Fall of 2005 one of the well known anti-dementia treatments changed its brand name. RAZADYNE made by Ortho-McNeil Neurologics, Inc., is the new name for the drug formally known as REMINYL. In addition, this drug has also been released in a once-a-day formulation and the new formulation is known as RAZADYNE™ ER. The following information is provided to answer the frequently asked questions about these changes.

Why did the drug change its name?

The reason for the name change was to avoid errors in filling prescriptions. To foster safe medication prescribing and dispensing, the manufacturer decided to change the brand name REMINYL to avoid confusion with the diabetes drug Amaryl® (glimepiride), marketed by Sanofi-Aventis. There have been several reports of prescribing and dispensing errors between these two drugs.

How is RAZADYNE different from REMINYL?

REMINYL and RAZADYNE are exactly the same medication—galantamine HBr. Only the brand name changed. RAZADYNE is the same as REMINYL in all other respects, including ingredients, dosage forms and strengths, appearance, and price.

What will I get when I fill my prescription?

Because the drugs are identical, pharmacists can fill REMINYL prescriptions with RAZADYNE without consulting your doctor. Also RAZADYNE prescriptions may be filled with REMINYL if your pharmacist has a remaining supply of REMINYL or does not yet have RAZADYNE available.

Will I always be able to get REMINYL?

You will be able to get galantamine HBr, however, it will soon only be available under the name of RAZADYNE. This is the safest way to ensure it is not confused with other medications.

Should I take both RAZADYNE and REMINYL together?

NO, you should not take RAZADYNE and REMINYL at the same time. To eliminate the possibility of confusion, please ask your doctor or pharmacist for a patient information sheet.

What is RAZADYNE ER?

RAZADYNE ER is the once-daily formulation of RAZA-

DYNE. It is the extended release formulation of the same drug and has been available in pharmacies since mid 2005.

How is RAZADYNE ER different from RAZADYNE?

The active ingredient is the same medication—galantamine HBr. However the dosage forms, strengths, and appearance are different. RAZADYNE™ ER is available in opaque hard gelatin extended-release capsules of 8 mg (white), 16 mg (pink), and 24 mg (caramel) containing galantamine hydrobromide.

How does this extended release form work?

The capsules use a tri-layer system to release the drug. Each capsule contains an immediate release layer made to deliver 25% of the total galantamine dose as an immediate release (IR) dose. This allows the drug to start working right away as it would in the original form. The other layers are an extended-release (ER) drug layer, and a rate controlling membrane. Together these 2 layers deliver the remaining 75% of the total dose as an extended-release (ER) dose. As the rate controlling membrane partially dissolves it releases the extended-release (ER) drug over 24 hours.

Is RAZADYNE ER better than RAZADYNE?

RAZADYNE ER only needs to be taken once a day. This may offer an advantage to some patients and their families.

Should I take RAZADYNE ER and RAZADYNE together?

No. These two drugs are the same medication but in different formulations. Taking them together may result in taking too much drug.

How can I find out more about drug treatment for Alzheimer's disease and decide if it is right for me or for someone in my family?

For more information about treatments for Alzheimer disease, go to the NYC Chapter web site: www.alznyc.org. For all questions about trying new medications, ask your doctor.

What else can be helpful?

Counseling and support for family members, proved to be effective by randomized controlled trials, is available through organizations like the Alzheimer's Association. Of course, it is also important to maintain your health, whether or not you have cognitive impairment. More information is available at www.alznyc.org and from the Alzheimer's Disease Education & Referral Center, a service of the National Institute on Aging, www.niapublications.org/adear.

Columbia University • Taub Institute • Clinical Trials

Safety and Tolerability of AAB-001 in Alzheimer's Disease

We are seeking men and women age 50 to 85 with mild-to-moderate AD to participate in a Phase IIA passive immunization study using the investigational drug, AAB-001. *If interested, please contact Evelyn Dominguez at 212-305-2371.*

Efficacy Study of MPC-7869 to Treat Patients with Alzheimer's Disease

We are seeking English and Spanish-speaking men and women, age 55 and older with mild-to-moderate AD to participate in a study to determine the effectiveness of MPC-7869 on cognitive and global function. MPC-7869 (Flurizan) is an anti-inflammatory drug that may also have an effect on beta-amyloid. *For more information, please contact Evelyn Dominguez at 212-305-2371.*

Valproate in Dementia (VALID) Study

This is a study to determine whether Valproate (a standard anticonvulsant medication) is effective in delaying or preventing the development of difficult behaviors such as agitation or psychosis in people with Alzheimer's disease (AD). This study will also determine whether Valproate slows the progression of AD. We are seeking English and Spanish-speaking men and women between 55 and 90 years of age to participate in the study. They must have a diagnosis of AD and have not experienced agitation or psychosis since the onset of AD. *If interested, please contact Ruth Tejeda at 212-305-766.*

Treatment of Mild Memory Loss Study

We are seeking men and women, age 45 or older, who have mild memory loss or mild cognitive impairment (MCI), to participate in a 12-month, placebo-controlled study to evaluate the effectiveness of donepezil (Aricept) on memory impairment. *For more information, please contact Evelyn Dominguez at 212-305-2371.*

Antipsychotic Medication Treatment of Psychosis and Behavioral Dyscontrol in Alzheimer's Disease Study

A research study funded by the National Institute of Aging will be treating people with AD who suffer from hallucinations, delusions, agitation, and/or aggression with risperidone, an FDA-approved antipsychotic medication. Each eligible participant must have a family member or caregiver who can assist with adherence to treatment and provide information during the research study. *For further information please contact Jenny Masmela at 212-543-6132.*

Mood and Memory Study

A study examining the benefit of treatment for depression in people (age 50+) with combined depression and mild memory problems is currently being conducted. In those depressed patients whose memory problem persists, further treatment

with medication to improve memory will be offered. *If interested, please contact Oliver Harper at 212-543-5067.*

Neuroimaging Studies

Alzheimer's Disease Neuroimaging Study

We are seeking English and Spanish-speaking men and women age 55 to 90, who have normal memory, or mild memory problems, or early Alzheimer's disease, to participate in a study to determine whether imaging of the brain with PET or MRI scans every 6 months can help predict and monitor the onset and progression of Alzheimer's disease. In addition to the neuroimaging, the study will collect blood and, for some participants, cerebral spinal fluid to determine if biomarkers can predict and monitor the disease. No medication will be prescribed. *To participate or get more information about the study please contact, Karina Stavitsky at 212-342-0522 or Rebecca Torgan at 212-305-1987.*

Amyloid and Glucose Brain Imaging Study in People with Memory Problems

Help us understand the chemical pathways in the brain using a procedure called PET. The PET scan involves the use of a radioactive marker, which is taken up by abnormal deposits, called amyloid deposits, in the brain. The PET camera will detect the signal it gives. A PET glucose scan and an MRI scan, which are standard clinical procedures, are also done in this study. Participants are reimbursed \$100 for a PET scan day and \$50 for an MRI scan. These procedures are performed once at an initial visit and then again one year later. The study is conducted at the Memory Disorders Center, NYSPI/Columbia University. *If interested, please call 212-543-5956. The study is for English speaking individuals aged 50-89.*

Other Studies

Normal Aging and Memory Study

We are seeking men over the age of 70, in good health, without memory problems who wish to participate in a research study on understanding normal aging and memory, may earn \$10/hr at Columbia-Presbyterian Medical Center (Research Foundation For Mental Hygiene). No medication is prescribed. *Call Sara Rosenblum at 212-543-5956 for more information. Spanish-speaking participants welcome.*

Genetic Linkage Study

We are seeking Caribbean Hispanic families from the Dominican Republic for a study to identify genes that may increase the risk for Alzheimer's disease (AD). *If you have at least two living family members diagnosed with AD, please call Vincent Santana at 877-636-5677 or Jennifer Williamson at 212-305-4655.*

Columbia University Medical Center *continued*

Additional Information Brain Donation Program “Give the Gift of Knowledge”

Brain donation allows valuable information to be obtained regarding normal aging and diseases that affect memory. This information may be useful towards the goal of developing more effective treatment strategies. If you or a family member wish to learn more about this program, please call Arlene Lawton, RN at 212-305-9086.

Lucy G. Moses Center for Memory and Behavioral Disorders

Changes in memory and thinking abilities can occur from a variety of conditions, not just Alzheimer’s disease. Taub Institute specialists offer a thorough multidisciplinary evaluation of memory and thinking difficulties at two locations: The Neurological Institute, 710 West 168th Street, New York, NY 10032; and Columbia Presbyterian Eastside, 16 East 60th Street, New York, NY 10022. For appointments call: 212-305-6939.

New York University School of Medicine Silberstein Institute For Aging and Dementia • Current Studies

Treatment Studies

Memantine (Namenda) and Patient-Centered, Comprehensive, Individualized Management of AD:

The goal of this study is to change the standard of care for AD patients by determining the added value of an individualized care management program for AD patients receiving memantine. Subjects with moderate to severe AD are eligible. All patients will be randomly assigned to one of two groups. Patients in both groups will receive memantine and follow-up evaluations. Additionally one group will receive an individualized management program consisting of home visits to get the patient exercising, doing enjoyable activities and cognitive stimulation, educational sessions for caregivers on coping with difficult situations and a caregiver support group to help with questions and emotional concerns. The duration of the study is six months. The contact person is Robyn Waters at 212-263-8088.

Mild Cognitive Impairment Study:

If you or someone you know are aged 45 to 90 and have mild memory loss, NYU School of Medicine is taking part in a national clinical research study to evaluate the safety and effectiveness of an oral, investigational medication for mild cognitive impairment. Qualified participants will receive complete study-related physical exams, lab work, electrocardiograms and cognitive evaluations at no charge while taking part in this study. For information and to find out if you or someone you know may be qualified, please call Robert L. Smith at 212-263-5708.

Huperzine A - AD Study:

Patients age 55 and older with Alzheimer’s disease are needed for a new study to determine the effectiveness of Huperzine A to treat the symptoms of Alzheimer’s disease. Huperzine A is a natural product extracted from a Chinese herb. There is growing evidence that Huperzine A not only compares favorably in symptomatic efficacy to cholinesterase inhibitors in current use, but additionally has both antioxidant and

neuroprotective properties, effects which may be relevant in the treatment of AD. For information and to find out if you or someone you know may be qualified, please call Robert L. Smith at 212-263-5708.

Biomarkers with Memantine Treatment

This investigator-initiated study is designed to examine the effects of memantine (drug approved for the treatment of moderate to severe AD) on CSF biomarkers of AD (amyloid beta, tau proteins and isoprostanes) and on the levels of brain metabolites as measured by proton magnetic resonance spectroscopy (H¹- MRS). Study recruitment includes normal individuals with subjective memory complaints, patients with mild cognitive impairment, and those with mild AD. Eligible subjects must be between 60 and 80 years of age. For information about participating in this project, please contact Dr. Lidia Sobanska, Center for Brain Health Coordination at 212-263-1091.

Early AD Diagnosis

Longitudinal Neuroimaging Study in AD:

We are currently taking part in the national Alzheimer’s Disease Neuroimaging Initiative (ADNI), a study sponsored by the National Institutes of Health (NIH). This multicenter study is being undertaken to find the most effective methods for tracking physical changes in the brain and in body fluids during the course of AD and to establish those methods as clinical standards. We will enroll patients diagnosed with AD (within the last year), patients diagnosed with mild cognitive impairment (MCI), and people with no memory complaints (other than the normal memory problems associated with age). Participants must be aged 55-90 and in general good health. All participants will receive standard neuropsychological testing, blood and urine tests and an MRI scan. Some participants will receive a PET scan and analysis of their cerebrospinal fluid (CSF). All

continued on NYCARE 4

Consejos Para Quienes Cuidan A Personas Con La Enfermedad De Alzheimer

Es necesario que la persona que se encarga de un individuo que padece de la enfermedad de Alzheimer considere ciertos reajustes. La planificación es sumamente importante para sostener la calidad de vida del paciente y de la persona encargada de su cuidado. Considere las siguientes sugerencias:

1. Conozca bien la enfermedad para formular un plan realista para el futuro.
2. Formule un plan para darle a la persona que se ha hecho cargo del paciente oportunidades de descanso, de manera que ésta persona no tenga que afrontar constantemente las dificultades de atender al paciente.
3. Brinde supervisión. Esté atento a los peligros en el hogar.
4. Asegure el bienestar médico de la persona con la enfermedad de Alzheimer. No existe cura y no hay tratamientos pero si hay algunos medicamentos disponibles que pueden ayudar a aliviar algunos de los síntomas, tales como la agitación, la depresión y el insomnio.
5. Ayude con el cuidado personal. Tome parte de las actividades diarias, como bañarse, vestirse y comer.

6. Para comunicarse más exitosamente el cuidador puede utilizar el lenguaje de gestos y señales debido a que el paciente probablemente tiene problemas para comunicarse.
7. Planee actividades que relajen al paciente como: bailar, hacer ejercicio, escuchar música, cantar canciones familiares, tocar instrumentos musicales ó actividades en el jardín como plantar flores.
8. Obtenga ayuda de los servicios disponibles, como los que ofrecen los centros de cuidado y las agencias que ofrecen ayuda y cuidados en el hogar.
9. Mantenga su propio bienestar porque podría cansarse. Tal vez, turnarse con otra persona para atender al paciente ó asistir a un grupo de apoyo. Siempre mantenga la fe.

Trate de obtener información con la gente de su comunidad. Para obtener mas información sobre la enfermedad de Alzheimer se puede comunicar con la Asociación de Alzheimer, Capítulo de la Ciudad de Nueva York al 212-983-6906 ext. 247.

—Por Isabel Guzman, RN

Queridos Amigos:

Los síntomas y las situaciones relacionadas con la enfermedad de Alzheimer y otros tipos de demencias son muy reales para muchos de ustedes. Existen aproximadamente 200,000 Latinos/Hispanos que sufren de la enfermedad de Alzheimer en los Estados Unidos y se anticipa de que estos aumentarán a 1.3 millones en el año 2050. Los Latinos/Hispanos tienen una tasa mas alta de enfermedades vasculares y al igual se pronostica que la expectativa de vida de nuestra comunidad aumentará hasta los 87 años de edad para el 2050. Todo esto significa que tienen aun gran riesgo de desarrollar la enfermedad de Alzheimer.



La enfermedad de Alzheimer y otras demencias relacionadas no solo afectan a las personas con la enfermedad pero también a sus seres queridos. Muchos de ellos se convierten en la única persona encargada de todas las necesidades de la vida diaria para el adulto que antes era independiente. Los papeles

Continúa en la siguiente página

En Esta Edición

Conferencia Anual Sobre La Etapa

Inicial de los Desordenes
de la Memoria

En Español 2

Esquina Para Los Cuidadores

En Español 3

Servicios en Español

En Español 4

Conferencia Anual Sobre La Etapa Inicial de los Desordenes de la Memoria

La Asociación de Alzheimer – Capitulo de la ciudad de Nueva York ofrecerá próximamente un simposio interactivo en Español dedicado a la comunidad Latina/Hispana con información sobre la enfermedad de Alzheimer y formas practicas de reducir la tensión.

Fecha: 25 de Abril del 2006

Lugar: The Graduate Center
365 Fifth Ave (entre las calles 34 y 35)

Hora: 8:30 am a 3:30 pm

NO SE OLVIDE DE ESTE EVENTO

Para más información o inscripción, llame a Alison Reynoso al 212-983-6906 ext. 247.

Alzheimer: Qué significa y que puede hacer

¿Desea usted mas información sobre la enfermedad de Alzheimer y otras demencias relacionadas? Este taller explorara los cambios que ocurren en personas que sufren de demencia incluyendo los síntomas, evaluación, medicamentos y comportamientos. TAMBIEN SE EXPLORARAN los pasos que usted puede tomar para mantener una comunicación productiva PARA USTED Y SU SER QUERIDO.

Cuidando de el cuidador

El proveer cuidado a una persona que padece de la enfermedad de Alzheimer u otra clase de demencia puede ser una tarea muy difícil. Acompañenos a explorar alternativas de cuidado personal mientras cuida de su ser querido. Al igual que las formas de reconocer y reducir la tensión física, mental y emocional. ¡Cuidemos del cuidador para que el/ella pueda seguir cuidando!

¿Está usted cuidando a un familiar con la enfermedad de Alzheimer?

Podría ser elegible para participar en una evaluación de una intervención de apoyo y consejería. Beneficios incluyen información acerca de la enfermedad de Alzheimer y recursos disponibles, apoyo y consejería para los cuidadores, servicios en español o inglés, y participación sin costo alguno. Si desea más información acerca de este proyecto, favor de comunicarse con la Dra. Carolina Gelman al 212.992.9731 o csr6@nyu.edu.

Queridos Amigos...Continuación de la página anterior

que antes desempeñaban ya no son efectivos y aunque es imposible volver a la vida de antes, existe la posibilidad de continuar una vida con dignidad, amor y respeto.

Los miembros de uno de nuestros grupos de apoyo han expresado la importancia de reunirse con personas que están viviendo situaciones similares. Ellos han encontrado un lugar seguro donde pueden desahogar sus penas y adquirir sugerencias de cómo manejar situaciones difíciles. El tener una idea de cómo comunicarse efectivamente con su ser querido cuando este no desea bañarse, el recordarse de mirar a la persona a los ojos y mantener la calma, el estar consciente de su tono de voz, el ser realista y el entender que la lógica ya no funciona hacen una gran diferencia. Al igual recomiendan que aquellas personas que cuidan de un individuo con problemas severos de la memoria busquen ayuda profesional y apoyo constante. El mantenerse informados sobre la enfermedad y los recursos disponibles pueden aliviar muchas de sus preocupaciones.

La Asociación de Alzheimer esta consciente de la importancia de crear programas de educación, ayuda y apoyo adecuados para la comunidad Latina/Hispana. La Asociación de Alzheimer ha ofrecido servicios en Español desde el 1998. Actualmente, la Asociación les ofrece una línea de ayuda disponible las 24 horas, 7 días a la semana, información sobre recursos disponibles, literatura sobre la enfermedad de Alzheimer, el programa de Safe Return y grupos de apoyo.

Si usted es la persona encargada del cuidado de un individuo con la enfermedad de Alzheimer u otro tipo de demencia, estamos aquí para servirles. Para más información, favor de llamarme al teléfono 212-983-6906 ext.247 o por correo electrónico al areynoso@alznyc.org.

Cordialmente,

Alison Reynoso

Alison Reynoso

Directora de Diversificación & Alcance

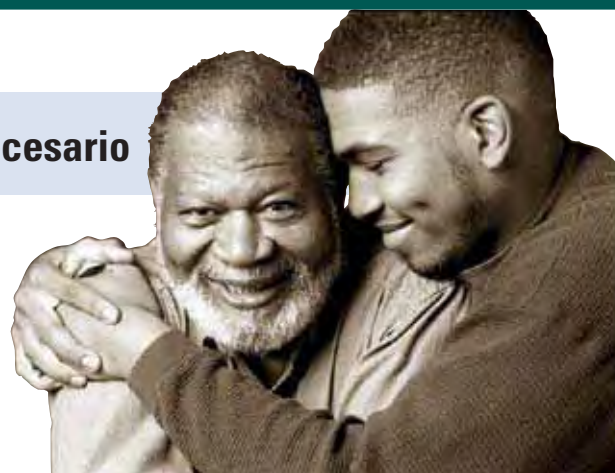
esquina para los cuidadores

Como Responder a Negligencia y Maltrato Innecesario

El Capitulo de la Ciudad de Nueva York ejerce diferentes funciones: educamos, informamos, apoyamos y ayudamos a las personas que sufren de la enfermedad de Alzheimer y desordenes relacionados, a los familiares de su cuidado y a los profesionales encargados de su atención. Nuestra organización nacional es líder mundial en el cuidado de la demencia y somos el mayor proveedor privado de fondos para la investigación así como también somos los lideres en la nación en nuestra misión de elevar las voces de las personas con demencia y sus familias en Washington, Albany y el Municipio de Nueva York. En muchas ocasiones proveemos testimonio en audiencias legislativas, ya sea a nivel de la Asamblea y Senado estatal o el Consejo municipal.

Recientemente intervine en una audiencia celebrada por el congresista Steve Englebright, Presidente del Comité sobre el Envejecimiento, sobre la necesidad de cuidados temporales. Varias familias a cargo de personas con Alzheimer de la organización de Fort Washington Senior Houses Services to the Elderly se unieron conmigo en este viaje. Muchos de estos ancianos al cuidado de personas con Alzheimer viajaron mas de una hora a pesar del frío y la nieve para contar sus historias personales y para reforzar la importancia de los servicios de cuidado diurno y los grupos de apoyo para ellos y sus familias.

Existe otro tipo de abogacía suministrado por el Capitulo de la ciudad de Nueva York para ayudar a las familias y garantizar el mejor cuidado posible para las personas que sufren de demencia. Frecuentemente, a través de nuestra línea telefónica las 24 Horas (Helpline), en nuestros grupos de apoyo y en nuestras reuniones educativas, se nos informa de situaciones en las cuales las personas requieren un defensor para garantizar el cuidado adecuado. En una de estas llamadas, la persona nos pidió que intercediéramos con su agencia de servicios en el hogar para obtener guantes de “latex” para el asistente del cuidado en el hogar. Los referimos al gerente del caso y a la enfermero/a coordinadora de la agencia correspondiente. En caso de que esta persona no recibiera una respuesta adecuada, le sugerimos que reportara el problema al Departamento de Salud del Estado, el cual tiene la responsabilidad de extender las licencias a las agencias de cuidado del hogar. Como consecuencia de su conversación con la agencia,



la persona recibió una respuesta satisfactoria.

Diariamente recibimos llamadas telefónicas de las familias de los residentes en Hogares de Adultos, Facilidades de Asistencia de Adultos y de asilos de ancianos – algunas de ellas expresando serias quejas que van desde casos en que los ancianos dementes son trasladados al hospital sin el acompañamiento de un personal adecuado y sin notificar a los miembros de la familia, cuestiones de falta de personal, (especialmente durante los fines de semana) casos en los cuales se dejan a los residentes sentados en su propio excremento por horas, reportes de falta de actividades, historial de manejo inadecuado de los medicamentos, observación de falta de higiene en el medio ambiente de la institución e incidentes en que los pacientes deambulan fuera de estas organizaciones. La hija de uno de los residentes reporto de que debido a personal inadecuado, su padre fue dejado en una silla en la ducha, desnudo, mojado y temblando de frío por mas de una hora, debido a que había un solo empleado.

Muchos de los familiares al cuidado de las personas que sufren de demencia se sienten intimidados por la administración de estas instituciones y tienen temor de expresarse públicamente. Una de nuestras funciones es asegurarse que no nos veremos nunca en la necesidad de tolerar un cuidado inadecuado, negligente y seriamente dañino. El Departamento de Salud del Estado de Nueva York cuenta con un “hotline” o servicio telefónico de urgencia para reportar problemas sobre los residentes de los asilos de ancianos y otras instituciones que requieren una licencia del estado – y por lo tanto, nosotros recomendamos a los familiares a que reporten sus quejas. Esto puede ser hecho de forma anónima, si existe miedo de venganza, pero nuestra experiencia nos demuestra que los residentes que tienen familias que son

Continúa en la siguiente página

Servicios en Español

Grupos de Apoyo

Estos grupos de apoyo están disponibles para aquellas personas que cuidan a un ser querido con problemas de la memoria. Venga a compartir sus experiencias y obtenga apoyo emocional y ayuda para desarrollar nuevas técnicas de cuidado.

Bronx: Grupo Bilingüe (Inglés & Español)

1st y 3rd Miércoles: 4:00 – 5:15 pm
Montefiore Medical Center, Bainbridge Avenue

Manhattan: Grupo en Español

1st y 3rd Jueves: 4:00 – 5:15 pm
Isabella Senior Resource Center, Calle 169th y Broadway

Lunes: 11:00 – 12:30 pm
Settlement Health, Calle 106th

Manhattan: Grupo en Español

Miércoles: 11:00 am – 12 noon
Ft. Washington Services for the Elderly, Calle 163rd

Queens: Grupo en Español

Miércoles: 2:00 – 3:00 pm
Elmhurst Senior Center, Broadway

Alzheimer's Association Safe Return®

El programa Alzheimer's Association Safe Return® ayuda a lograr el regreso seguro de individuos con Alzheimer o una demencia relacionada, que deambulan y se pierden.

Para más información acerca del registro en el programa Alzheimer's Association Safe Return®, por favor llame a Elizabeth Santiago al 212-983-6906 ext. 205.

Información sobre la Enfermedad de Alzheimer

Ofrecemos información sobre la enfermedad de Alzheimer y otros tipos de demencia. Los familiares aprenderán acerca de recursos y servicios que los pueden ayudar a enfrentar desafíos presentes y los planes para el futuro.

Miércoles, 8 de Mayo

Hora: 5:30 – 7:00 pm

Lugar: Alzheimer's Association, NYC Chapter
360 Lexington Avenue – piso 5
(Entre las calles 40 y 41)

Para más información sobre como asistir a un grupo de apoyo o/y la orientación favor de llamar a Alison Reynoso al 212-983-6906 ext. 247.

Advertencia Publica

Nuestra hoja electronica informativa en el sitio web www.alz NYC.org contiene información importante relacionada con la enfermedad de Alzheimer.

esquina para los cuidadores...

Continuación de la página anterior

defensores activos reciben mejor cuidado debido a que estas instituciones saben que hay alguien velando por el miembro de dicha familia.

Es particularmente importante para esta vulnerable población de las personas con demencia, que no pueden expresarse por ellos mismos, el tener personas responsables y atentas a sus intereses y que puedan hablar en su defensa. Esta es una misión crítica para nosotros, pero necesitamos identificar los casos en que existe un mal cuidado o donde la vida y el bienestar de las personas se ponen en peligro. Necesitamos que ustedes estén conscientes que abogar por el cuidado, el hablar, y el tomar acción son las únicas formas en que estas situaciones mejoraran. Si no exigimos mejores cuidados, no existirán incentivos para proveerlos.

Mi mensaje en el día de hoy es que todos debemos de seguir de cerca los protocolos para la resolución de problemas en las agencias e instituciones que proveen cuidado, pero si esta meta no se alcanza, debemos buscar ayuda. Llame al capitulo de la ciudad de Nueva York, llame a nuestras organizaciones asociadas, y llame a los Departamentos de Salud del Estado y de la Ciudad para presentar su queja – Pero, por favor, llame – solo podemos solucionar el problema si sabemos que existe.

Para más información, no duden en llamar a la Asociación de Alzheimer, Capitulo de la ciudad de Nueva York 800.272.3900 o a nuestras organizaciones asociadas:

- 1) **FRIA** – Friends and Relatives of Institutionalized Aged
Teléfono: 212-732-4455
- 2) **CIAD** – Coalition of Institutionalized Aged and Disabled
Teléfono: 212-481-7572
- 3) **LTCC**– The Long Term Care Community Coalition
Teléfono 212-385-0355
- 4) **NY State Department of Health**
 - i. Para expresar una queja, incluyendo abuso sobre una institución licenciada por el Estado:
Teléfono: 1-866-893-6772
 - ii. Quejas sobre asilo de ancianos:
Teléfono: 1-888-201-4563
 - iii. Quejas sobre agencias de servicios en el hogar:
Teléfono: 1-800-628-5972

Sinceramente,
Jed Levine
Director de Programas

Si desea leer la versión completa de este artículo, favor de visitar nuestra pagina web www.alz NYC.org y presione En Español.

New York University School of Medicine *continued*

subjects will be repeatedly assessed every 6 months for 2 to 3 years. For further information, please contact Dr. Kenneth Rich or Shantel Williams at 212-263-7563.

Longitudinal Study of Normal Aging, Mild Cognitive Impairment (MCI) and Alzheimer's Disease (AD):

Participants receive a comprehensive diagnostic evaluation and will be evaluated every two years. The goal of this project is to improve the early diagnosis and to better understand the clinical course and causes of age-related cognitive decline and Alzheimer's disease. For more information, please call Emma Shulman at 212-263-5756.

Longitudinal Study of Human Gait (walking ability):

The purpose of this federally funded grant project is to determine whether quantitative measures of human gait pattern can improve the early detection (and/or allow accurate prediction of possible subsequent decline) to Alzheimer's disease, particularly among elderly differing widely in levels of education. This project will specifically test gait function, using both computerized and non-computerized assessment techniques. The gait assessments require about 15 – 20 minutes to complete. The study is open to participants with normal cognitive function, mild cognitive impairment (MCI) and Alzheimer's disease, enrolled at the NYU Alzheimer's Disease Center. Please contact Alvin Wagner at 212-263-2619.

Position Emission Tomography (PET) & Memory Study:

These NIH funded programs are designed to use advanced brain imaging techniques to measure the anatomy and metabolic function of the brain so as to predict future cognitive impairment. The on-going two-year longitudinal imaging studies of healthy elderly individuals has helped us better understand the differences between successful aging and the progression to memory impairment and to Alzheimer's disease. We are developing and testing a profile of measures to identify those at increased risk for future memory impairment. Study recruitment includes normal individuals between 20-90 years and individuals with memory problems. For information about participating in these projects, please contact Shantel Williams, Center for Brain Health Coordination at 212-263-7563.

Cerebral Spinal Fluid (CSF):

This study is designed to develop a specific early AD diagnosis based on analysis of cerebrospinal fluid. This NIH supported project will evaluate whether the amount and type of amyloid beta and tau proteins (proteins associated with AD) and isoprostanes (product of lipid peroxidation) that are found in the cerebrospinal fluid are related to memory changes and the brain shrinkage determined from MRI studies. The objective of this program is to develop a screening test for early

AD. Study recruitment includes normal individuals between 40 and 90 years of age, individuals with memory problems, mild cognitive impairment, and AD. For information about participating in this project, please contact Dr. Kenneth Rich, Center for Brain Health Coordination at 212-263-7563.

Helping Caregivers

Support for Couples Dealing With a Recent Diagnosis of AD:

A unique free counseling study has been designed especially for couples and is supported by a grant from the Alzheimer's Association. During 6 weekly meetings, together with a counselor, couples will discuss problems resulting from the illness and workable responses to them. Couples will be encouraged to share thoughts and feelings, and find ways to help and support each other. For further information, please call Cynthia Epstein, ACSW at 212-263-1056 or Ursula Auclair, LCSW at 212-263-2245.

Compare the Effects of the NYU Intervention on Rural and Urban Caregivers:

This study for adult-children of a parent with Alzheimer's disease will be conducted simultaneously in New York City and rural Minnesota. All participants will have access to resource information and support from experts as needed. Those in the enhanced group will meet with a counselor individually and with other family members. Based on an earlier research program, we expect that all participants will experience significant benefits to their well-being. For further information, please call the study coordinator, Olanta Barton at 212-263-5710.

For Caregivers of Parents in the Middle Stage of AD:

The study investigates an education and support intervention designed to reduce the stress, anxiety, and depression frequently experienced by people whose parents are in the moderate stage of Alzheimer's disease. The goal of this study is to help caregivers provide a more stimulating environment for their parents and have a positive experience interacting with them and providing care. Everyone who enrolls will receive self-teaching materials especially written for this project. For further information, please call Olanta Barton at 212-263-5710.

Are you caring for a relative with Alzheimer's Disease?

You may be eligible to participate in an evaluation of a counseling and support intervention. Benefits include information about Alzheimer's disease and available resources, support and counseling for caregivers, services in Spanish and English, and participation at no cost to you. If you would like more information, please contact Dr. Caroline Gelman at 212-992-9731 or csr6@nyu.edu.

continued on NYCARE 5

New York University School of Medicine *continued*

Brain Donation Program:

Participants at the Alzheimer's Disease Center are eligible to participate in a free autopsy program that provides families with a definitive diagnosis and contributes to important

research on the causes and treatment of brain aging and Alzheimer's disease. For further information, please contact Tricia Spoto at 212-263-5108.

Mount Sinai School of Medicine • Clinical Trials

Homocysteine (HC) Study:

The purpose of this randomized, placebo-controlled study is to determine whether reduction of homocysteine levels with high dose folate/B₆/B₁₂ supplementation will slow the rate of cognitive decline in subjects with Alzheimer's disease. Homocysteine is an amino acid (a building block of proteins) found in the bloodstream. Blood levels of homocysteine are elevated in AD, and these high levels may contribute to the disease. Patients over the age of 54 with Alzheimer's disease are eligible. All study medications are free of charge. For more information, please contact our research coordinator at 212-241-8329. *GCO# 91-208(11), MSSM awaiting IRB approval*

A Multi-Center, Double-Blind, Placebo-Controlled Therapeutic Trial To Determine Whether Natural Huperzine-A Improves Cognitive Function

The objective of this research study is to determine whether natural Huperzine-A improves cognitive (thinking/memory) function of patients diagnosed with Alzheimer's disease (AD). Huperzine-A is a natural *cholinesterase inhibitor* (stops the breakdown of helpful chemicals in the brain) and is extracted from the Chinese herb *Huperzia serrate*. There is evidence which suggests that Huperzine-A may be as effective as the medications currently approved by the FDA for the treatment of AD. Patients over the age of 55 who have a diagnosis of Alzheimer's disease and who are not currently taking one of the FDA approved medications for AD (except Namenda) are eligible to participate. For more information, please call our ADRC research coordinator at 212-241-8329. *GCO #04-0418, Principal Investigator: Dr. Hillel Grossman, MSSM IRB approved through 8/31/06*

Alzheimer's Disease Neuroimaging Study:

Subjects 55-90 years old (healthy controls, those with memory complaints, or Alzheimer's disease) needed for a study to determine whether neuroimaging (e.g., MRI) can predict the onset or progression of Alzheimer's disease. The study will also collect blood and, for some participants, cerebral spinal fluid. Patients will be compensated for their time. For more information, please call 212-241-8329. *Principal investigator: Dr. Mary Sano; GCO#91208-12; MSSM IRB approved through 5/31/06.*

Protective/Risk Factors for AD in Healthy Adults:

This study aims to identify biological factors that might either predispose or protect individuals from developing Alzheimer's disease. The 2-3 hour interview would be completed at the subjects' home. A small blood sample is drawn to allow investigators to examine possible protective factors. Participants will be compensated for their time. Men and women who are 85+ years old with no memory impairment or dementia will be eligible for the study. If interested, please call the Family Studies Office at 718-584-9000, ext. 2713. *GCO #84-119 MSSM awaiting IRB approval*

Brain Tissue Donation Program:

Through the generous act of post-mortem brain donation, families have the opportunity to partner with Mount Sinai in research designed to develop more effective treatment strategies for Alzheimer's disease. We have specially trained staff available to discuss the tissue donation process, and any related questions that you and your family might have. For more information, please contact Karen Dahlman, Ph.D. at 212-241-1844. *GCO #84-119 and #79-141 MSSM awaiting IRB approval*

Note: Spanish-speaking participants are welcome in all studies. All study participants receive reimbursement for any related expenses. Participants without AD receive monetary compensation for their time.

If you are interested in any of the above research studies, please contact the Alzheimer's Disease Research Center at 212-241-8329. Mount Sinai also has Satellite clinics specializing in AD and other Memory Disorders located at:

Elmhurst Hospital in Queens: 718-334-3983

Bronx VA Medical Center: 718-584-9000 x5199

Program Director...continued from page 3

their interests and speaking out on their behalf. This is a critical mission for the NYC Chapter, but we need your help to identify where there is poor care or where people's lives and well being are at risk. We need you to know that advocating for care, speaking up, and taking action is the only way that these situations improve. If no one demands better care, there is no incentive to provide it.

We have a number of partners in the advocacy area with many years of experience helping families work with residential facilities to get the best care possible. FRIA, celebrating its 30th year of superb advocacy on behalf of the institutionalized aged, CIAD (Coalition for Institutionalized Aged and Disabled), the NYS Long Term Care Community Coalition (LTCCC), and the NYC Long Term Care Ombudsman Program, all are key players in the pursuit of good care for persons in residential settings and ensuring that their rights are upheld. Our government is also becoming more active. In December, NYS Attorney General Elliot Spitzer issued a report on the issue of safe staffing in nursing homes, and is investigating abuse and neglect in two nursing homes upstate.

My message today is that we all need to follow the protocols for problem resolution in the agency or institution that is providing care, but if that doesn't work, reach out for help. Call the NYC Chapter, call our advocacy partners and call the City and State Health Departments to register a complaint. But do call – we can only fix a problem when we know we have one.

—Jed A. Levine
Executive Vice President,
Director of Programs & Services

Correction

Please note the following which was inadvertently omitted from the Fall 2005 Newsletter, Caregivers' Corner article on Who is Aggressive in Alzheimer's Care?

Dr. Ladislav Volicer, MD, PhD was Recipient, Hearthstone Alzheimer's Family Foundation Fourth Annual Barry Reisberg Award for Non Pharmacologic Research and Practice.

FRIA

FRIA's mission is to assure that nursing home residents receive prompt, high quality and compassionate care, which fosters their dignity and independence. Even more broadly we seek high quality, long-term health care for all New Yorkers in the least institutionalized setting possible. We accomplish this by helping relatives become effective advocates for the needs of their loved ones. Our main tools are our telephone hotline, publications, organizing and assisting family councils within nursing homes, and training workshops for family members and professionals.

212-732-4455 • www.FRIA.org

CIAD

CIAD's purpose is

- To organize and strengthen the Coalition as a powerful advocacy organization for the rights of adult home and nursing home residents.
- To help individuals resident councils develop into effective groups in each facility.
- To work on Federal, State and local regulatory issues that affect residents quality of life.
- To help residents to become more independent and achieve self-determination.

212-481-7572 • www.ciadny.org

LTCCC

LTCCC is devoted to improving care for the elderly and disabled. We work to ensure that long term care consumers, who are often very vulnerable, are cared for safely and treated with dignity.

212-385-0355 • www.ltccc.org

NYC LTC OMBUDSMAN PROGRAM

NYC LTC Ombudsman Program has trained volunteers to act as advocates in nursing homes and adult homes.

11 Park Place, New York, NY 10007

212-962-2720 • www.ltcombudsman.org

New York State Department of Health

- To file a complaint, including abuse, regarding Certified Adult Care Facilities, 866-893-6772.
- Nursing Home Patient Care Complaints
888-201-4563
- Complaint line for Licensed Home Care Agencies
800-628-5972

Education Calendar

Spring 2006

MONDAY April 3

Legal/Financial Seminar
Time: Noon – 1:30 p.m.
Place: Chapter Office

WEDNESDAY April 5

Easing The Transition From Home To
A Residential Care Facility
Time: 6:00 – 8:00 p.m.
Place: Chapter Office

THURSDAY, April 6

Understanding Dementia: What You Need
To Know And Where To Go
(Meeting held in Queens)
Time: 12:30 – 2:00 p.m.
Place: Samuel Field YM-YWHA
Cape Conference room
59-28 Little Neck Parkway
Little Neck, NY

Medicaid Home Care Seminar:
A Practical Guide To The System
Time: 5:30 – 7:00 p.m.
Place: Chapter Office
Note: Prior attendance at a Legal/Financial
Seminar required.

FRIDAY April 7

Understanding Dementia: What You Need
To Know And Where To Go
Time: Noon – 1:30 p.m.
Place: Chapter Office

MONDAY April 10

Educational Meeting
Time: 6:00 – 7:30 p.m.
Place: Chapter Office
Topic: Coping with Alzheimer's Disease:
Three Workshops on the Early,
Middle and Late Stages
Facilitators: New York City Chapter Staff

TUESDAY April 11

Understanding Dementia: What You Need
To Know And Where To Go
Time: 5:30 – 7:00 p.m.
Place: Chapter Office

MONDAY April 17

Medicaid Home Care Seminar:
A Practical Guide To The System
Time: Noon – 1:30 p.m.
Place: Chapter Office
Note: Prior attendance at a Legal/Financial
Seminar required.

MONDAY April 17 cont.

Legal/Financial Seminar
Time: 5:30 – 7:00 p.m.
Place: Chapter Office

Understanding Dementia: What You Need
To Know And Where To Go
(Meeting held in Brooklyn)
Time: 6:00 – 7:30 p.m.
Place: Family Resource Center
1 Prospect Park West
Brooklyn, NY 11215

WEDNESDAY April 19

Understanding Dementia: What You Need
To Know And Where To Go
Time: 5:30 – 7:00 p.m.
Place: Chapter Office

TUESDAY April 25

Understanding Dementia: What You Need
To Know And Where to Go
Time: Noon – 1:30 p.m.
Place: Chapter Office

THURSDAY April 27

Legal/Financial Seminar
Time: 5:30 – 7:00 p.m.
Place: Chapter Office

MONDAY May 1

Legal/Financial Seminar
Time: Noon – 1:30 p.m.
Place: Chapter Office

WEDNESDAY May 3

Easing The Transition From Home To
A Residential Care Facility
Time: 6:00 – 8:00 p.m.
Place: Chapter Office

THURSDAY May 4

Understanding Dementia: What You Need
To Know And Where To Go
(Meeting held in Queens)
Time: 12:30 – 2:00 p.m.
Place: Samuel Field YM-YWHA
Cape Conference room
59-28 Little Neck Parkway
Little Neck, NY

Medicaid Home Care Seminar:
A Practical Guide To The System
Time: 5:30 – 7:00 p.m.
Place: Chapter Office
Note: Prior attendance at a Legal/Financial
Seminar required.

SATURDAY May 6 & 13

Meeting the Challenges of Alzheimer's
Caregiving: A Two-Part Workshop for
Family Members
Time: 9:30 a.m. – 3:30 p.m.
Place: Chapter Office
Note: Attendance at both sessions is expected.

MONDAY May 8

Understanding Dementia: What You Need
To Know And Where To Go (in Spanish)
Time: 5:30 – 7:00 p.m.
Place: Chapter Office

Educational Meeting
Time: 6:00 – 7:30 p.m.
Place: Chapter Office
Topic: The Grieving Process: Understanding
and Living with Feelings of Loss and
Grief as a Caregiver
Speaker: Benyamin Cirlin, LCSW, Director,
Center for Loss and Renewal

TUESDAY May 9

Understanding Dementia: What You Need
To Know And Where To Go
Time: 5:30 – 7:00 p.m.
Place: Chapter Office

FRIDAY May 12

Understanding Dementia: What You Need
To Know And Where To Go
Time: Noon – 1:30 p.m.
Place: Chapter Office

MONDAY May 15

Medicaid Home Care Seminar:
A Practical Guide To The System
Time: Noon – 1:30 p.m.
Place: Chapter Office
Note: Prior attendance at a Legal/Financial
Seminar required.

Legal/Financial Seminar
Time: 5:30 – 7:00 p.m.
Place: Chapter Office

Understanding Dementia: What You Need
To Know And Where To Go
(Meeting held in Brooklyn)
Time: 6:00 – 7:30 p.m.
Place: Family Resource Center
1 Prospect Park West
Brooklyn, NY 11215

Education Calendar

Spring 2006

WEDNESDAY May 17

Understanding Dementia: What You Need To Know And Where To Go
Time: 5:30 – 7:00 p.m.
Place: Chapter Office

TUESDAY May 23

Understanding Dementia: What You Need To Know And Where To Go
Time: Noon – 1:30 p.m.
Place: Chapter Office

THURSDAY May 25

Legal/Financial Seminar
Time: 5:30 – 7:00 p.m.
Place: Chapter Office

THURSDAY June 1

Understanding Dementia: What You Need To Know And Where To Go
(Meeting held in Queens)
Time: 12:30 – 2:00 p.m.
Place: Samuel Field YM-YWHA
Cape Conference room
59-28 Little Neck Parkway
Little Neck, NY

Medicaid Home Care Seminar: A Practical Guide To The System

Time: 5:30 – 7:00 p.m.
Place: Chapter Office
Note: Prior attendance at a Legal/Financial Seminar required.

MONDAY June 5

Legal/Financial Seminar
Time: Noon – 1:30 p.m.
Place: Chapter Office

TUESDAY June 6

Understanding Dementia: What You Should Know And Where To Go
(A Meeting for Professionals)
Time: 9:30 – 11:00 a.m.
Place: Chapter Office

WEDNESDAY June 7

Easing The Transition From Home To A Residential Care Facility
Time: 6:00 – 8:00 p.m.
Place: Chapter Office

FRIDAY June 9

Understanding Dementia: What You Need To Know And Where To Go
Time: Noon – 1:30 p.m.
Place: Chapter Office

MONDAY June 12

Educational Meeting
Time: 6:00 – 7:30 p.m.
Place: Chapter Office
Topic: Alzheimer's Disease: Research and Treatment Update
Speaker: Howard A. Crystal, M.D., Director, Alzheimer's Disease and Memory Disorders Center, University Hospital of Brooklyn

TUESDAY June 13

Understanding Dementia: What You Need To Know And Where To Go
Time: 5:30 – 7:00 p.m.
Place: Chapter Office

MONDAY June 19

Medicaid Home Care Seminar:
A Practical Guide To The System
Time: Noon – 1:30 p.m.
Place: Chapter Office
Note: Prior attendance at a Legal/Financial Seminar required.

Legal/Financial Seminar

Time: 5:30 – 7:00 p.m.
Place: Chapter Office

Understanding Dementia: What You Need To Know And Where To Go
(Meeting held in Brooklyn)
Time: 6:00 – 7:30 p.m.
Place: Family Resource Center
1 Prospect Park West
Brooklyn, NY 11215

WEDNESDAY June 21

Understanding Dementia: What You Need To Know And Where To Go
Time: 5:30 – 7:00 p.m.
Place: Chapter Office

THURSDAY June 22

Legal/Financial Seminar
Time: 5:30 – 7:00 p.m.
Place: Chapter Office

TUESDAY June 27

Understanding Dementia: What You Need To Know And Where To Go
Time: Noon – 1:30 p.m.
Place: Chapter Office

Legal...continued from page 16

changes to become law in New York, the state must first adopt enabling legislation. At this time, it is not clear when this law will become effective in New York. This could happen during the current legislative session. It is also not clear how the law will be applied to transfers occurring after the Federal effective date but before New York adopts enabling legislation. The ultimate treatment may depend upon when the Medicaid application was filed or when a determination is made by the Medicaid agency. In 1993, the last time we had major Federal Medicaid legislation, New York State did not adopt the legislation until the following year but it still applied to transfers after the Federal date of enactment.

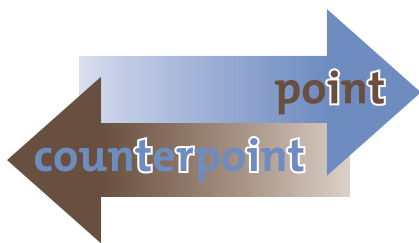
There are many other provisions in the DRA which limit your ability to do advance planning. It is critical that you get your affairs in order while you still have the opportunity.

PLEASE NOTE:

ALL MEETINGS ARE FREE OF CHARGE AND SUBJECT TO CHANGE. Please call 800.272.3900 for more information and to reserve a seat. Reservations are *mandatory* for all meetings.

The NYC Chapter Office is located at 360 Lexington Avenue (between 40th & 41st Streets), 5th floor, New York, NY 10017.

We wish to thank the following for their generous donation of space for the meetings: CAPE at the Samuel Field YM-YWHA and Park Slope Geriatric Services.



Keep Your Brain Fit...*continued from page 10*

flexibly and helps to promote ‘brain reserve’ in the event that some connections are lost. Physical activity appears to help the brain in a different way – by increasing chemicals in the brain that help protect it and making it more resistant to injury. Fortunately, common everyday types of physical activity seem to make a difference, such as walking a mile, or going up and down stairs. The lungs help supply the brain with oxygen and it is therefore not surprising that improved lung function helps the brain. Response to stress and feelings of self-worth may be the reason that feelings of ‘self-efficacy’ were related to maintenance of mental ability. Self-efficacy was measured by asking people how much they felt they made a difference in the daily activities on which they depended (such as getting reasonable medical care or transportation). With stress, there are high levels of hormones that are not good for the brain. Thus, it may be that people who feel they have less control over the daily activities that make a difference in their lives, have higher levels of these stress hormones.

In addition to the role that each of these four factors play in promoting mental ability over time, it is important to emphasize that maintaining a healthy heart also helps to maintain a healthy brain. In other words, what is good for the heart is good for the brain. Thus, factors that protect the heart, such as keeping your cholesterol low, using aspirin to prevent blood clots, and keeping your blood pressure under control protect both your heart and your brain. This is because the blood supply of the heart is closely connected to the brain and the same factors that can damage the vessels of the heart can also damage the blood vessels in the brain. Thus, relatively simple changes in daily life can help keep your brain fit.

—Marilyn S. Albert, Ph.D.

Keep Your Mind Open...*continued from page 10*

benefit in lowering blood pressure, lowering cholesterol and reducing the risk of heart disease have often added a cognitive assessment. To date none of these studies have demonstrated a benefit on cognition or a reduction of dementia.

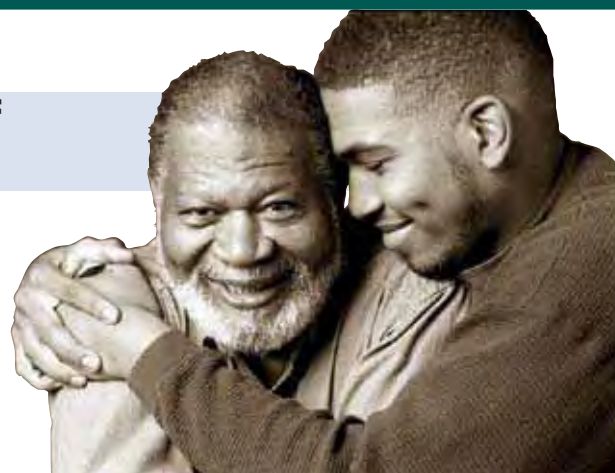
So what is a person to do? Of course it makes sense to take care of your health, to reduce your cardiovascular risk factors, to exercise and follow your doctor’s advice. However, there are at least two important reasons to avoid lulling ourselves into thinking that we can change our risk of dementia and cognitive loss. The first is to avoid blaming the victim. Alzheimer’s disease has no known cause and a person’s disease cannot be blamed on their life style. Such a conclusion can cause an unreasonable burden of guilt on patients and their families.

Even more importantly, we need to acknowledge that the answer can only be addressed by research. We need to keep our minds open to new ideas that may lead to real prevention. As stakeholders in our own cognitive future we need to personally support and participate in research at every level. We need to inform policy makers, local and national authorities and both private and public agencies of our expectation of funding for both basic science and clinical research. Telling our representatives that we expect a commitment to increasing funding for dementia research gives a voice to finding an answer. We also need to make it our mission to maximize participation in research. Estimates are that less than 1% of the population participate in Alzheimer’s disease research. Partnering with the scientific community, staying informed about research topics, and participating in research is the only way to find the true answers. There are many opportunities. For example, supporting a decision of family or friends to consider research, volunteering time to assist a patient to participate or participating ourselves in studies focused on prevention are all important contributions to the future of our own cognitive health.

—Mary Sano, Ph.D.

caregivers' corner

Enhancing The Nutritional Status of People with Alzheimer's Disease



For the person with Alzheimer's, good nutrition is essential to maintain optimal health and well being. When nutritional status is compromised, individuals may experience weight loss, increased confusion, skin breakdown, incontinence, weakness, increased infections and falls. This leads to a decreased ability to chew and swallow food.¹ The ultimate outcome is a limited ability to perform activities of daily living and an increased dependence on their caregiver.

Ensuring that the person with Alzheimer's disease (AD) receives adequate nutrition is by no means simple, but a few nutrients have been shown to be essential in maintaining nutritional health.

Omega-3 Fatty Acids

Chronic inflammation, due to the interaction with the processing and build up of beta-amyloid peptide, has been implicated as a possible trigger of AD. Beta-amyloid peptide, mixed with cell remnants, creates abnormal, sticky plaques that are toxic to nerve cells and considered to be either a cause of or a by-product of Alzheimer's disease.

Omega-3 fatty acids are a type of polyunsaturated fat found largely in fish. Containing anti-inflammatory properties, these fats may help regulate the inflammatory response of many diseases, including AD. In fact, in some studies, fish eaters have been found to have lower rates of AD² and reduced accumulation of beta-amyloid. This has also been observed in mice fed docosahexaenoic acid, an omega-3 fatty acid found in seafood³. Considered essential fats since they cannot be made in the body, omega-3 must be supplied by the diet. Good food sources of omega-3 fatty acids include cold water fish (salmon, herring, mackerel, trout, sardines, light tuna, catfish), walnuts, flaxseed and canola oil. However, these studies are epidemiological, and create an intriguing association between diet and AD, but do not prove causality. It is important to remember that despite these studies, we all know individuals who have eaten fish as a part of their diet and still had AD. Currently, there aren't any dietary recommendations for omega-3 intake for people with AD. However, it makes sense to follow the American Heart Association's recommendation to eat fish at least twice a week.

Folic Acid, Vitamin B-6 & Vitamin B-12

Homocysteine is a blood protein that, when elevated, may increase the risk of cardiovascular and AD⁴. Although it is unclear how homocysteine affects the brain, its levels can be normalized by adequate dietary intake of folate, vitamin B-6 and vitamin B-12. These three vitamins function synergistically; therefore it is important to include all in a healthy diet. Since 1998, folate has been added to all breads, pastas, rice and cereals in the US. Other sources include: orange juice, spinach, asparagus, lentils and kidney beans. Vitamin B-6 is found in cereals, chickpeas, rice, potatoes, turkey, fish and prune juice. Food sources of vitamin B-12 are animal products (meats and dairy), as well as, fortified soymilk and cereals. To ensure that the patient is getting their daily requirements of these vitamins, provide a multivitamin that meets the daily value for all three. (Folic acid: 400 micrograms, vitamin B-6: 2 milligrams, vitamin B-12: 6 micrograms).

This is the first in a series of articles on the nutritional and feeding needs of persons with AD. If you have specific nutritional questions, please submit them to Patricia Slinger at Pslinger@GLWD.org or Jlevine@alznyc.org.

—Patricia Slinger-Harvey, MPH, RD, CDN & Lisa Zullig, MS, RD, CDN of God's Love We Deliver

God's Love We Deliver, (GLWD), a non-profit agency in NYC, provides meals to men, women and children affected by HIV/AIDS, cancer, AD and many other serious illnesses who are unable to shop or prepare meals for themselves. The agency's team of experienced nutritionists also provides nutrition education, information and counseling in individual and group sessions to clients, their caregivers and other service providers. In partnership with GLWD, the NYC Chapter is pleased to offer this service to our clients. For information, please call the Chapter's 24-hour Helpline at 800.272.3900.

Patricia Slinger-Harvey is the Director of Nutrition Services at GLWD and Lisa Zullig is a staff Nutritionist. For individualized nutrition information, the nutrition department of GLWD can be reached at 212.284.8103/800.747.2023 or by visiting www.godslovewedeliver.org.

1 Roberts et al. *Alzheimer's Care Quarterly*. Fall 2002. 3(4):316-329.

2 Morris et al. *Arch Neurology*. 2003 Jul;60(7):940-6.

3 Lim et al. *The Journal of Neuroscience*, Mar 23, 2005,25(12):3032-3040.

4 Seshadri et al. *N Engl J of Med*, vol.346,no.7, Feb 14, 2002.

SUPPORT GROUP OPENINGS

The NYC Chapter sponsors over 140 family caregiver support groups. Some groups are for spouses or adult children, others are mixed - made up of all caregivers. Generic groups are for caregivers of all long-term illnesses. Before attending a support group, call the group leader and schedule a personal interview. We recommend you attend "Understanding Dementia: What You Need to Know and Where to Go" at the Chapter office. Call the Helpline at 800-272-3900 to register. Most support groups are open for new members, however, the following groups are actively seeking members. Call Wendy Panken, Support Group Manager at 212-983-6906 ext. 214 or visit our web site at www.alznyc.org for a complete list of support groups.

BRONX

Adult Children's Groups

Hebrew Home at Riverdale (Palisades Ave)

DAY: Tuesdays

TIME: 6:30 – 8:00 PM

CONTACT: Rina Ginat 718-581-1628

Riverdale Senior Services (Netherland Ave)

DAY: 1st & 3rd Mondays

TIME: 6:00 – 7:30 PM

CONTACT: Wendy Bolton 718-884-5900 x19

Mixed Groups

Riverdale YM/YWHA (Arlington Ave)

DAY: 2nd & 4th Tuesday

TIME: 10:30 AM – 12:00 PM

CONTACT: Randi Schwartz 718-548-8200 ext. 226

Shervier Nursing Care Center

DAY: every other Wednesday

TIME: 6:00 – 7:30 PM

CONTACT: Catherine Burke 718-548-1700 x392

Beth Abraham Health Services Center

(Allerton Ave)

DAY: 1st & 3rd Wednesdays

TIME: 6:00 – 7:15 PM

CONTACT: Hilary Horvat 718-519-4068

Morningside House (Pelham Parkway)

DAY: 1st & 3rd Tuesdays

TIME: 2:00 – 3:00 PM

CONTACT: Helen John 718-409-8284

Bronx VA Medical Center (W. Kingbridge Ave)

DAY: 1st & 3rd Fridays

TIME: 10:00 – 11:15 AM

CONTACT: Linda Torres 718-584-9000 ext. 6946

(for spouses of veterans)

Spouses' Groups

Hebrew Home at Riverdale

DAY: Tuesdays

TIME: 11:30 AM – 1:00 PM

CONTACT: Deborah Rubin 718-581-1627

Rosehill Apartments (Southern/Kazmiroff Blvd)

DAY: 1st & 3rd Tuesdays

TIME: 11:00 – 12:30 PM

CONTACT: Annelen Madigan 718-584-5101

BROOKLYN

Adult Children's Group

Sheepshead Bay Services for the Elderly (Ave O)

DAY: every other Tuesday

TIME: 6:30 – 8:00 PM

CONTACT: Alice Curry 718-375-3377

Mixed Groups

Sunrise Assisted Living (Sheepshead Bay)

DAY: every other Tuesday

TIME: 7:00 – 8:15 PM

CONTACT: Sophie Finkelman 718-646-2973

Brooklyn Alzheimer's Disease Assistance

Center (Lenox Road)

DAY: Wednesdays

TIME: 2:30 – 3:30 PM

CONTACT: Lorna Walcott-Brown 718-287-4608

Long Island College Hospital (Hicks St)

DAY: 1st & 3rd Wednesdays

TIME: 7:00 – 8:30 PM

CONTACT: Bonnie Weinstein 718-834-0731

Brighton Beach (West 5th St)

DAY: 1st & 3rd Thursdays

TIME: 3:00 – 4:30 PM

CONTACT: Jack Pollock 212-721-3537

Bensonhurst Senior Assistance Center

DAY: every other Tuesday

TIME: 6:30 – 8:00 PM

CONTACT: Mary Hume 718-236-3205

Metropolitan Jewish Health Systems

(Boro Park/Bensonhurst - 62nd St)

DAY: 1st & 3rd Tuesdays

TIME: 6:00 – 7:15 PM

CONTACT: Iren Kalishevich 718-621-3600

Park Slope Geriatric Day Center

(Prospect Park West)

DAY: Tuesdays

TIME: 6:00 – 7:30 PM

CONTACT: Priscilla Swan 718-499-7701 ext. 137

Spouses' Group

Young Israel of Bedford Bay (Sheepshead Bay)

DAY: Tuesdays

TIME: 10:00 – 11:30 AM

CONTACT: Toby Abramson 516-484-3188

MANHATTAN

Adult Children's Groups

Upper Westside (West 80's)

DAY: 1st & 3rd Wednesdays

TIME: 6:00 – 7:30 PM

CONTACT: Ginny Abrams 212-663-6414

Cabrini Medical Center (East 19th St)

DAY: 1st & 3rd Wednesdays

TIME: 6:15 – 7:30 PM

CONTACT: Diane McKenna 212-995-6483;

Hank Weit 212-995-6572

360 Lexington Ave (40th & 41st Sts)

DAY: every other Wednesday

TIME: 12:30 – 1:45 PM

CONTACT: Lorraine Ruggieri 212-362-6500

St. Vincent's Hospital (W 12th St)

DAY: every other Thursday

TIME: 2:30 – 4:00 PM

CONTACT: Rosemarie Greene 212-604-7332

360 Lexington Ave. (40th & 41st St)

DAY: every other Friday

TIME: 12:30 – 1:45 PM

CONTACT: Pat Estess 718-858-0918

Sophie Finkelman 718-646-2973

C.V. STARR (1st Ave & 85th St)

DAY: 1st & 3rd Tuesdays

TIME: 6:00 – 7:30 PM

CONTACT: Ken Onaitis 212-879-7400 x116

Lenox Hill Neighborhood House (E 70th St)

DAY: Tuesdays

TIME: 6:30 – 8:00 PM

CONTACT: Christopher Chin 212-744-5022 x1266

Mixed Groups

LifeCare Services (5th Ave & 37th St)

DAY: 1st & 3rd Thursdays

TIME: 12:30 – 1:45 PM

CONTACT: Shelley Miller 212-768-1228

Educational Alliance (Grand St)

DAY: every other Monday

TIME: 6:00 – 7:15 PM

CONTACT: Bonnie Errico 212-358-8489

Council Senior Center (West 72nd St)

DAY: Fridays

TIME: 12:00 – 1:30 PM

CONTACT: Ruth Rothbart-Mayer 212-799-7205

Ft. Washington Houses Services for the Elderly

(W 163rd St)

DAY: Thursdays

TIME: 11:00 AM – Noon

CONTACT: David Currier or Carmen Nunez 212-927-5600

DOROT (West 85th St)

DAY: 2nd & 4th Tuesdays

TIME: 11:00 AM – 12:30 PM

CONTACT: Reva Mager 212-769-2850

Greater Harlem Nursing Home

(W 138th St between Lenox and 5th Ave)

DAY: 2nd & 4th Mondays

TIME: 4:00 – 5:15 PM

CONTACT: Cliff Kennedy 212-690-7400 ext. 263

Harlem Hospital Geriatric Center (W 135th St)

DAY: 2nd & 4th Wednesdays

TIME: 2:00 – 3:30 PM

CONTACT: Naomi Ellis 212-939-3239 or

212-939-3232

Educational Alliance (Grand St)

DAY: Wednesdays

TIME: 1:30 – 2:30 PM

CONTACT: Francine Shore 212-358-8489 x313

Isabella Senior Resource Center (W 169th St)

DAY: 1st & 3rd Thursdays

TIME: 4:00 – 5:15 PM

CONTACT: Alison Reynoso 212-983-6906 x247

Judy Nunez 212-543-4645

(for Spanish speaking caregivers)

NYU Medical Center (1st Ave & 31st St)

DAY: Thursdays

TIME: 10:30 AM – Noon

CONTACT: Emma Shulman or Gert Steinberg

212-263-5756

VA Medical Center (1st Ave & 23rd St)

DAY: Tuesdays

TIME: 1:00 -2:00 PM

CONTACT: Abby Miller 212-686-7500 x3625

Carolyn Greene 212-686-7500 x770

SUPPORT GROUP OPENINGS

S.A.G.E. (7th Ave between 27th & 28th St)

DAY: Mondays
TIME: 6:00 – 7:30 PM
CONTACT: Catherine Thurston 212-741-2247 x227
(for gay & lesbian caregivers)

Lincoln Square Neighborhood Center (W 65th St)

DAY: 1st & 3rd Wednesdays
TIME: 5:45 – 7:15 PM
CONTACT: June Aaronson 212-319-6188
Susan McAuley 212-254-3582

Liberty Street (Wall Street area)

DAY: 1st & 3rd Wednesdays
TIME: 12:30 – 1:30 PM
CONTACT: Glee Kleinberg 212-686-5818

Spouses' Groups

West 79th Street (Central Park West)

DAY: every other Monday
TIME: 10:00 – 11:15 AM
CONTACT: Marjorie Hornik 212-222-8990

East 75th St

DAY: 1st & 3rd Wednesdays
TIME: 12:30 – 1:45 PM
CONTACT: Judith Young 212-988-1809

360 Lexington Ave (40th & 41st Sts)

DAY: 1st & 3rd Mondays
TIME: 10:30 AM – noon
CONTACT: Wendy Panken 212-983-6906 ext. 214

360 Lexington Ave (40th & 41st Sts)

DAY: 2nd & 4th Wednesdays
TIME: 4:00 – 5:30 PM
CONTACT: Reva Hoffman 212-983-6906 x212

360 Lexington Ave (40th & 41st Sts)

DAY: Thursdays
TIME: 12:30 – 1:45 PM
CONTACT: Sharon Shaw 212-983-6906 x203

JASA (West 60's)

DAY: every other Thursday
TIME: 2:00 – 3:30 PM
CONTACT: Susan Katz 212-273-5254

Daughters' Groups

360 Lexington Ave (40th & 41st Sts)

DAY: Tuesdays
TIME: 12:30 – 1:30 PM
CONTACT: Sharon Shaw 212-983-6906 x203

360 Lexington Ave (40th & 41st Sts)

DAY: 1st & 3rd Wednesdays
TIME: 6:45 – 8:15 PM
CONTACT: Jeanne Lieb 212-496-1198

West 56th St (Broadway)

DAY: Thursdays
TIME: 12:15 – 1:30 PM
CONTACT: Deborah Rubin 212-757-4202

Generic Groups

Shira Ruskay Center at JBFCS (7th Ave at 54th St)

DAY: every other Thursday
TIME: 3:15 – 4:30 PM
CONTACT: Sandy April 212-399-2685 x230;
Wendy Panken 212-983-6906 x214
(All caregivers whose relatives are in a nursing home or at home with 24/7 homecare.)

Lenox Hill Neighborhood House (East 70th St)

DAY: Wednesdays
TIME: 6:30 – 8:00 PM
CONTACT: Paula Grooms 212-744-5022 x 1205
(Adult children living at a long distance and caring for parents with any long term progressive disabling illness.)

QUEENS

Adult Children's Groups

C.A.P.E. /Samuel Field YM-YWHA

(Little Neck Parkway)
DAY: every other Wednesday
TIME: 7:00 – 8:30 PM
CONTACT: Joan Baraf 718-224-0566

New Parkway Hospital (213th St-Forest Hills)

DAY: every other Thursday
TIME: 7:00 – 8:30 PM
CONTACT: Lorraine Greenberg 516-942-4515 or
516-942-4500

Mixed Groups

Catholic Charities (Flushing)

DAY: Tuesdays
TIME: 10:15 – 11:45 AM
CONTACT: Fran Staples 718-358-3541

Elmhurst Senior Center (Roosevelt Ave/Broadway)

DAY: Tuesdays
TIME: 4:30 – 5:30 PM
CONTACT: Licet Valois Gonzalez 718-478-7171 x27
(for Spanish speaking caregivers)

Sunnyside Community Services (39th St)

DAY: 2nd & 4th Tuesdays
TIME: 5:00 – 6:30 PM
CONTACT: Fern Parker 718-392-6945

Elmhurst Hospital Center (41st Ave & 80th St)

DAY: 2nd & 4th Mondays
TIME: 3:00 – 4:30 PM
CONTACT: Fatima Farinas 718-334-2809

Spouses' Groups

S.N.A.P. Caregiver Program (Queens Village)

DAY: Mondays
TIME: 10:00 – 10:45 AM
CONTACT: Isobella Ustoyev 718-740-6519
(Telephone support group)

Granat Alzheimer's Center

Parker Jewish Institute (at Long Island Jewish Hospital)
Day: 1st & 4th Wednesdays
TIME: 11:00 – Noon
CONTACT: Martha Wolf 718-289-2105

Self Help Clearview Senior Center (Bayside)

DAY: Tuesdays
TIME: 10:15 – 11:15 AM
CONTACT: Ellen Sarokin 718-631-1886

Telephone Support Groups

DOROT's Caregivers Connections

CONTACT: Lori Rubin 212-769-2850

Public Policy...continued from page 14

Term Care Restructuring Initiative which includes a comprehensive waiver program to include all long term care services, Medicaid eligibility changes, and expansion of the public/private insurance program, the NYS Partnership for Long Term Care. To accomplish the restructuring, SDOH will develop a waiver application to the federal Centers for Medicare and Medicaid.

Also, SDOH and the State Office for Aging (SOFA) will seek implementation of a Point of Entry (POE) system initially to provide information on long term care services to all ages regardless of income, screening to determine individual needs, and assistance in obtaining services. Both the restructuring initiative and the POE are huge undertakings that will affect the Alzheimer's

community, and the chapter will actively follow their development.

The NYC Chapter continues to address the importance of home, community-based and residential care to the Alzheimer's community. In December, Jed Levine, EVP, Dir. of Programs & Services, presented testimony on Caregiver Support/Respite Services for Caregivers of Older New Yorkers to the hearing held by Assembly Standing Committee on Aging. He expressed the value of respite and adult day care and described the issues for Alzheimer's families. He stressed the need for funding for program availability, program expansion, and program affordability.

—Ann Berson

Vice President, Director of Public Policy

Reflections...continued from page 17

take care of yourself, you need to find a solution that works for you. It sounds like that's what you've done. Jim, how has your background helped you construct a financial plan that ensures ongoing care for Jackie? What can you teach others?

JL: I'm now living on the income and principal of what money I have. So I did one thing that would raise an eyebrow if one of my brokers sold this product to a 77-year old client for the benefit of his 75-year old wife, healthy or not. I bought two immediate pay annuities. If I die, that money is Jackie's and will go for her support. When she dies, the remainder of principal that hasn't been paid out already will go to the children. The reason I did this is to create a paying agent for dishing out a regular, orderly stream of income.

LEB: It's a form of financial discipline.

JL: Yes. The removal of that money from my grasp has exercised a discipline. I now have to be careful with money. It helped that I don't want a lot. All of my extravagances are of energy and creativity.

LEB: That's an excellent piece of advice -- look for resources that enforce discipline.

JL: To get that money out of harm's way.

LEB: Let's talk about when you visit Jackie

JL: When I arrive, I say, "Honey, I'm home!" I peck her on the cheek, pat her little hand, watch the Hallmark Channel, slip away to the computer room, bat out an e-mail, and have lunch with Jackie on the terrace while she is fed by hand. She eats better now than when she was 100% -- and it takes about an hour.

LEB: So you're getting tremendous gratification from the fact that she's thriving?

JL: I'm getting gratification from being in love with life.

LEB: And Maria knows you care. Did you have any concerns or reservations about going public? For a long time, so few talked about Alzheimer's.

JL: I am what I call a minor celebrity, as a result of having been on radio and TV as Jim "Built By Bonds" Lebenthal. When you are a fixture in someone's living room or bedroom night after night, you become one of their family. So I am talking to my own when I try to detoxify and de-stigmatize a disease that one could have a problem talking about to strangers. While it's okay to have a broken leg, you're not supposed to lose your mind.

LEB: In this job, one of the things that is gratifying is helping people focus on the caregiver. Our 24-hour Helpline, Care Consultation, Diversity and Outreach, support groups, and education efforts focus equally on the person with the disease and the caregiver.

JL: You can't get through this disease without a caregiver. This is a "Velcro" disease - you and the caregiver are attached.

LEB: Alzheimer's engages the whole family in some way or another. And someone has to assume responsibility.

JL: My responsibility has been to myself. You cannot hold me up as a model. If I am a model, I'm a lucky model from whom you can borrow a tiny bit -- that is that the caregiver must be cared for. What is best for Jackie is best for me.

LEB: It allows you your freedom, knowing that she's well taken care of. That's a lesson for many people. You are very much a model, because you're taking care of yourself while still providing the best care possible for your wife.

There is another part of your story that is a model for many families; agreement that one person is the primary caregiver, capable of making decisions and being the responsible party. Most of the time it's the spouse, but not always. The other members of the family can be equally invested both emotionally and sometimes financially, but one person must take responsibility and make the hard decisions.

JL: In business and in most situations in life, there is a constant giving and taking and negotiating, listening to the other side. I listen to the other side, I listen and then I do what I know I need to do. People argue, "What kind of quality of life is this? Why don't you put her in a nursing home?"

LEB: And you know in your heart that you are doing the right thing for her.

JL: Yes I do!

LEB: There is the family of the person with the disease, including the incontrovertible decision maker and then there is this extended family that evolves over time including medical professionals, caregivers and social workers. We care for them too, so that when they go into your home, you have a partner. In your case, Maria has become your partner.

In less than 50 years, 1 out of every 5 New Yorkers

continued on page 33

Reaching out to all New Yorkers

NYC has become as diverse as the world. Alzheimer's disease (AD) does not discriminate and has become one of the leading public health crises of the 21st century. For instance, it has been projected that during the first half of the 21st century, the number of Hispanic elders suffering from AD and related dementias could increase to 1.3 million by 2050 in the U. S. (approximately 200,000 today). This report was released in 2004 by the Alzheimer's Association. Age is a risk factor for AD in all racial and ethnic groups. The Latino/Hispanic population is the fastest growing population in the U. S. Key findings from this report project that this population will have the greatest life expectancy of all ethnic groups increasing to age 87 by 2050. According to an article published by the Alzheimer's Association, "The Silent Epidemic," the number of African-Americans age 65 and over will more than double by 2030, from 2.7 million in 1995 to 6.9 millions by 2030. Latinos/Hispanics and African-Americans have a higher rate of vascular disease which may put them at risk for AD and related dementias.

The NYC Chapter created the Diversity & Outreach initiative to extend program services to underserved and ethnically diverse populations, primarily the Latino/Hispanic population (since 2001), and is managed by Alison Reynoso. We offer the following services to Spanish speaking individuals:



Alison Reynoso

- Culturally and linguistically appropriate education meetings at the Chapter and at community-based organizations.
- Development and availability of a Language Library (materials in Spanish and 9 other languages).
- 24-hour Helpline (800.272.3900) offering information, referrals and support with translation services available in over 140 languages, including Spanish.
- Representation at Spanish radio station WADO, newspapers El Diario and HOY, and television interviews at New York 1 and Channel 47.
- Development of a quarterly newsletter in Spanish and expansion of our En Español web site at www.alznyc.org.

- Participation at community coalitions and advocacy groups.
- Development of 5 support groups for caregivers in Spanish.
- Alzheimer's Association Safe Return® information, support and enrollment assistance from Chapter staff.

Diversity Expansion:

The Chapter has expanded its Diversity & Outreach program to encompass the needs of the African-American population. The Chapter recognizes that in order to reach out to African-Americans there needs to be a specific focus designed to attract a greater percentage of the population than has been represented in the past.

In November, 2005, Rosemary Irving was hired as African-American Outreach Manager to meet the special needs of this population within the five boroughs, focusing on providing Chapter core services. These include education, information and referrals, outreach, support groups, advocacy and the Safe Return program. The first step will be to identify churches and organizations to partner with, in order to disseminate Chapter information. The second step will be to design initiatives to encourage members in the community to take advantage of the services. The ultimate goal is to have a greater representation of African-Americans in all of the opportunities available at the Chapter, including support group leadership, volunteering, Board membership and other service groups.



Rosemary Irving

The Latino outreach component will expand programs and services to Spanish speaking professionals and community members. Our 1st strategy will be to create a Chapter point of services site, located at the center of a NYC Latino/Hispanic populated area. This will establish easier access for local residents to all Chapter programs & services. Our 2nd strategy will be to increase the number of trainings designed for professionals in Spanish.

—Alison Reynoso,
Manager, Diversity & Outreach &
Rosemary Irving,
African-American Outreach Manager

volunteer spotlight: Our Valuable Volunteers

Our busy office serves all 5 boroughs of NYC, fulfilling hundreds of requests from people anxious to receive information on Alzheimer's disease, caregiving, Chapter meetings and events. We send frequent mailings to thousands about our upcoming events, both educational and social. Despite a dedicated staff, we could not do it all without our wonderful group of volunteers.

Volunteers work in a variety of ways. At the Chapter office, our trained Helpline Counselors provide telephone assistance on our 24-hour Helpline, while others help out assisting in clerical tasks. Volunteers also help to make our special events such as our annual Memory Walk and Caregiver Soirée huge successes. Volunteers with special expertise are encouraged to assist in those areas where their experience can best be utilized.

Many long-standing volunteers are well informed about all aspects of our operation. Our newest members, often

high school and college students, bring their much appreciated up-to-date computer skills to the mix.

Based on research from www.independent.org, the value of volunteer time is estimated at \$17.55 per hour. Our Chapter saves about **\$72,000** per year because of our outstanding volunteer support. This support enables us to maintain our record as one of the leading charities, where 82 cents of every dollar raised goes directly to Chapter programs and services.

Most of our volunteers have been touched on a personal level by a family member or friend affected with AD. Their understanding and compassion of the problems involved are reflected in the quality of their commitment.

If you would like to join them, please call 212-983-6906 ext. 241.

—Amanda Levine

Director of Volunteer Leadership & Development

Staff *Transitions & Achievements*

We are very pleased to welcome Rosemary Irving as the first Outreach Manager to the African-American community. Rosemary, a licensed clinical social worker with vast nonprofit experience, will be responsible for developing programs to meet the specific needs of NYC's African-American clientele, designing and implementing public education campaigns that will provide critical information about AD and the wide array of support services provided by the Chapter.

A native New Yorker, with an impressive range of expertise as a social worker, psychologist and administrator in both the public and private sectors, and a clinical psychotherapist, Rosemary holds a B. S. degree from Russell Sage College, a Masters of Social Welfare degree from UCLA, and has completed Post Masters Educational Studies at C.G. Jung Institute for Analytical Psychology. She is a member of the National Association of Social Workers, the National Association for the Advancement of Psychoanalysis, and the Women's Psychotherapy Referral Service.

We also welcome Amanda Leis, LMSW, Manager of Care Consultation. Amanda has extensive experience in the field of Aging. She was the Director of the Home Outreach Program for the Elders at Hartley House and the Director of Project WEST for JASA. She holds a B. A. degree from Wheaton College, a Masters of Arts degree from Jewish Theological Seminary of America and a Masters of Science in Social Work with a specialization in Gerontology from Columbia University School of Social Work. Amanda's clinical skills and 13 years of

work in the field will prove enormously valuable to clients and families who will benefit from her advocacy and her ability to help guide families in the complexities of care planning.

AS SEEN IN THE EAST SIDE **OUR TOWN** COMMUNITY BUILDER

Lou-Ellen Barkan, Chapter President and CEO had the honor of being selected as the first-place winner of the prestigious OTTY *Community Builder Award*. This award recog-



nized her efforts on behalf of the Alzheimer's community. The OurTown Community Builder included an interview, in which Lou-Ellen shared how her personal experiences turned into a career. She shared how working with Mayor Giuliani and her own family experiences with dementia aided her determination to help the agency connect with individuals and effect change in public policy.

Visit www.alznyc.org for the complete article.

Development Report

Philanthropic support is crucial to the Chapter's ability to carry out its programs and services. With this issue, we will be highlighting programs and the funders who helped to make them possible. We thank all of our friends for their support. We could not do our work without you.

With the help of three funders, whose support totals \$130,000, our Emergency Room Training Program will be expanded to 14 hospitals throughout NYC. This important program, under the direction of Della Frazier-Rios, MS, RN, VP, Dir. of Education & Outreach, helps to ensure physicians, nurses, and other key personnel have the educational tools necessary to identify AD patients as well as treat and refer them appropriately. We wish to thank The Bodman Foundation for its \$50,000 grant, The New York Community Trust for its \$30,000 grant, and The Starr Foundation for its \$50,000 grant. The Starr Foundation's grant was part of a total award of \$150,000, of which \$100,000 is for general operations.

Findings from a recent study concluded that AD is more prevalent among African-Americans than among Caucasians, and that African-Americans tend to be diagnosed at a later stage of AD. Funding from Ortho-McNeil Neurologics, Inc., will be used to help identify and address the special needs of the African-American community. Ortho-McNeil Neurologics is also supporting our 6th Annual Early Stage Memory Disorders Forum as well as Chapter special events.

The Fan Fox and Leslie R. Samuels Foundation Inc. is also supporting this important outreach program with a two-year grant of \$40,000 to fund Alzheimer's Association Safe Return® public awareness and registration in the African-American community.

Clinical Services comprises both our 24-hour Helpline and Care Consultation. Our Helpline receives, on average, close to 700 calls per month. Callers who require special assistance are referred to our care consultants, who offer individual short-term counseling and support for family caregivers and persons with AD. A \$20,000 gift from Mrs. Helen Galland Loewus is helping to support this important program.

Eisai Inc., and Pfizer Inc are supporting Clinical Services as well by underwriting our Helpline information packets. The two companies are also supporting Chapter special events.

Our Emergency/Special Assistance Fund, which provides immediate, short-term financial assistance for clients who are desperately in need of financial support, received grants of \$25,000 from FJC and \$18,000 from the NYC Chapter Junior Committee.

And, our 2nd Annual Caregiver Soirée, held on November 14th at Au Bar, in NYC, was underwritten by a generous grant from SeniorBridge, Inc.

We wish to especially acknowledge Forest Pharmaceuticals, Inc., for underwriting this Spring issue. The newsletter is an invaluable resource for the community and reaches close to 50,000 New Yorkers affected by AD.

In closing, we extend our thanks to all the donors who supported our year-end campaign. As of January 31st we have raised \$440,125, a 40% increase over FY05, and a record-breaking achievement for the Chapter.

If you would like more information about our programs and how you can support the Chapter, please call Carol Berne, Vice President for Leadership Giving at 212.983.6906 ext. 243 or cberne@alznyc.org.

Lotos Club Event

On December 12th, Board member Anne McBride Schreiber hosted a cocktail reception at the Lotos Club for friends and supporters of the NYC Chapter. Guest speaker, Rudolph E. Tanzi, Ph.D, of Harvard Medical School and Massachusetts General Hospital, and co founding scientist of Prana Biotechnology, provided a research update on advances in the genetics of Alzheimer's disease.



ways to give

The Alzheimer's Association, New York City Chapter, depends upon philanthropic support to carry out its important mission. Your generosity enables us to sustain our excellence in programs and services and develop innovative model programs to ensure that we continue to meet the needs of the Alzheimer's community.

Here are some ways you can make a gift to the New York City Chapter:

- **CHECKS:** Please make checks payable to the Alzheimer's Association, New York City Chapter and mail to:

Alzheimer's Association, New York City Chapter
360 Lexington Avenue, 5th Floor
New York, New York 10017

For your convenience, a self-addressed postage paid envelope has been provided in this newsletter.

- **CREDIT CARD:** You may use your credit card to make a gift **on-line** by visiting www.alznyc.org and clicking on [Make a Donation](#). We accept MasterCard, Visa and American Express. Please be assured that we have a secure server for all credit card transactions. You may also make a credit card gift by calling 212-983-6906 ext. 204 or 240.

- **APPRECIATED SECURITIES:** Gifts such as stocks or bonds may offer substantial tax advantages. A full fair market value deduction is allowed provided the security has been held more than one year (long term capital gain property); otherwise, the deduction is limited to the donor's adjusted tax basis.

- **BEQUESTS:** By remembering the Alzheimer's Association, New York City Chapter in your will, you can have a significant impact on improving the quality of care for all those affected by Alzheimer's disease. Your bequest may have estate tax planning benefits as well.

Here is sample bequest information you can take to your attorney:

I, _____(city, state, zip), give, devise and bequeath to the Alzheimer's Association, New York City Chapter, with offices located at 360 Lexington Avenue, 5th Floor, New York, New York 10017 (insert written amount of gift, percentage of the estate, or residuary of estate, or description of property) for its unrestricted use and purpose.

- **LIFE INSURANCE AND RETIREMENT PLANS:** You may also choose to remember the Alzheimer's Association, NYC Chapter by naming the Chapter the beneficiary of your [Retirement Plan](#) or [Insurance Policy](#).

- **TRIBUTE GIFTS:** Gifts to the Alzheimer's Association, New York City Chapter provide a special opportunity to honor the memory of a family member, friend or colleague, or to recognize an individual or a life occasion.

- **MATCHING GIFTS:** Your company may have a matching gifts program. Matching gifts can double or even triple your contribution. Please contact your company's Human Resources Department to see if your company is eligible.

- **PAYROLL DEDUCTIONS:** If your employer conducts an employee contribution program through the United Way or one of the other federated campaigns, please remember to designate the Alzheimer's Association, New York City Chapter on your campaign form. The following is a sample of employee payroll deduction programs:

Combined Federal Campaign (CFC)	9001
C.U.N.Y. & Combined Municipal Campaign (CMC)	0737
State employee Federal Appeal (SEFA)	51-1322
United Way	003004

- **CORPORATE GIVING:** There are many ways your corporate employer can support the Alzheimer's Association, New York City Chapter, including payroll deductions, sponsoring Memory Walk or forming a Memory Walk Corporate Team, supporting our *"Forget-Me-Not" Gala* or by making a corporate contribution to a Chapter program or service. If you volunteer with the Chapter, your company may have a special contributions program available for volunteers.

If you have any questions about your gift or would like to discuss gift opportunities, please contact **Carol Berne, Vice President for Leadership Giving**, at 212-983-6906 ext. 243, or by e-mail at cberne@alznyc.org. All inquiries are handled with prompt and confidential attention. As you consider any Charitable Gift Plan, please consult with your advisor to determine the tax/financial implications for you and your family.

The Alzheimer's Association, NYC Chapter is a tax-exempt organization under Section 501 (c) (3) of the Internal Revenue Code (Tax ID number 13-3277408) and your gifts are tax deductible to the full extent of the law.

tributes

in memory of...

Ms. Myra Abramson
From Toby's Friend Terri
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Ms. Fredda Klopfer
Laura & Harry Kuper
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Mr. George Loughran
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Introducing the New York City Chapter *HonorGift* Tribute Program

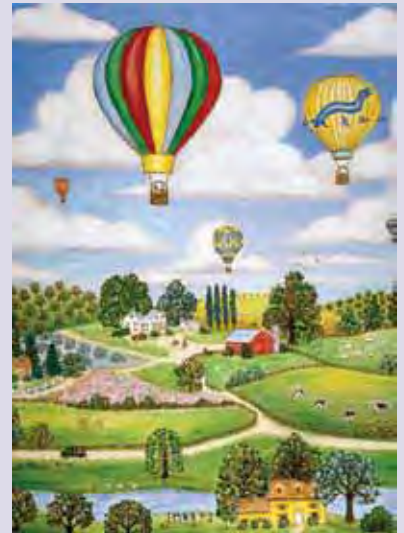
HonorGift tributes provide a special opportunity to honor the memory of a family member, friend or colleague, or to recognize an individual or life occasion.

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Autumn Sanctuary



Ballooning Over Country 1

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- In Honor Of - Ballooning Over Country 1
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- Phone us at 212-983-6906, or
- Visit our web site at www.alznyc.org

A minimum gift of \$30 is required for all *HonorGift* cards. For bulk orders (*i.e.* for graduations, weddings, etc) please contact Carol Berne at cberne@alznyc.org or call 212.983.6906 x243.

Reflections...continued from page 25

will either have AD - or be taking care of someone who does. So when your friends are questioning how you handle your situation, you can ask them to call you again when they share your experience - because in a few years we'll all have this problem.

JL: These days there is almost no one who doesn't have a relationship with this disease, so it has to be acknowledged and accepted. I always say we're not talking about death; we are talking about life, the business of living. It is nice that we are on the same wavelength.

LEB: Agreed - and many, many thanks Jim, for talking with us today.

Jim Lebenthal, municipal bond salesman and self-described "incorrigible showman," joined the Lebenthal family bond business after 12 kaleidoscopic years as a reporter, movie maker, TV producer, and adman. Pound for pound, the name Lebenthal sold more municipal bonds than any other firm on Wall Street. Producer of an Oscar nominated short subject film "*T is for Tumbleweed*," Jim's new book, "*Confessions of a Municipal Bond Salesman*," will be published this spring. Jim graduated from Princeton University and lives in NYC.

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Please know that unless you see

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The following organizations **ARE NOT** affiliated with the Alzheimer's Association:

- American Health Assistance Foundation
- Alzheimer's Foundation of America – AFA
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If you have any questions, please call the New York City Chapter at 212-983-6906 ext. 243.

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The NYC Chapter has created a beautiful collection of Sterling Silver and Vermeil (24K Gold-plated Sterling Silver) "Forget-Me-Not" jewelry, including pendants, earrings (pierced and clip-on) and bracelets.



New items in time for Mother's Day, Father's Day and Graduations, include men's cuff links, available in Sterling Silver or Vermeil, and our bangle bracelets are now available in a larger size.



Visit the *alznyc* store "Jewelry Boutique" at www.alznyc.org. Orders may be placed on-line, by phone at 212.983.6906 ext. 200, or by mail using this order form.



Bracelets

	<u>Unit Price</u>	<u>Qty</u>	<u>Total</u>
Alzheimer's Awareness Purple Wristbands (pkg of 10)	\$10 .00	_____	_____
"Forget-Me-Not" Sterling Silver bangle size: <input type="checkbox"/> standard <input type="checkbox"/> large	\$60.00	_____	_____
"a reason to hope" Sterling Silver bangle size: <input type="checkbox"/> standard <input type="checkbox"/> large	\$60.00	_____	_____
Both bangle bracelets size: <input type="checkbox"/> standard <input type="checkbox"/> large	\$100.00	_____	_____
"a reason to hope" Sterling Silver Cuff bracelet for men & women	\$75.00	_____	_____

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Polished Sterling Silver pendant with Sterling chain and pierced earrings	\$50.00	_____	_____
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Polished Vermeil pendant with gold-filled chain and pierced earrings	\$60.00	_____	_____
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Polished Sterling Silver pendant with Sterling chain and clip-on earrings	\$55.00	_____	_____
Antiqued Sterling Silver pendant with Sterling chain and clip-on earrings	\$55.00	_____	_____
Polished Vermeil pendant with gold-filled chain and clip-on earrings	\$60.00	_____	_____
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Polished Sterling Silver clip-on earrings	\$35.00	_____	_____
Antiqued Sterling Silver clip-on earrings	\$35.00	_____	_____
Polished Vermeil clip-on earrings	\$35.00	_____	_____
Antiqued Vermeil clip-on earrings	\$35.00	_____	_____

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Polished Sterling Silver cuff links	\$35.00	_____	_____
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BULLETIN BOARD

Meeting the Challenges of Alzheimer's Caregiving: A Two-Part Workshop for Family Members

Presented by Della Frazier-Rios,
Vice President, Director of Education & Outreach

May 6 & 13, 2006

9:30 a.m. – 3:30 p.m.

Chapter Office

PART I (Saturday, May 6th)

Overview of the Illness & Communication

PART II (Saturday, May 13th)

Behaviors & Activities

REGISTRATION IS REQUIRED. ATTENDANCE AT BOTH SESSIONS IS EXPECTED.

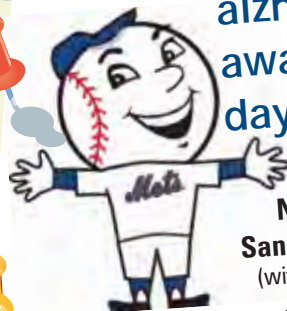
PLEASE CALL 800-272-3900.

Attendance is limited to 20 participants. Light refreshments will be served.

Support Group Leader Training Seminar

April 21, April 28, May 5, & May 12, 2006
Registration requires a commitment to attend all 4 days of training. To register, for information about future workshops, or ongoing supervision groups for support group leaders, please call Sharon B. Shaw, LCSW, CGP, at 212.983.6906, ext. 203.

alzheimer's awareness day at shea



NY Mets vs San Diego Padres
(with Mike Piazza!)

Wednesday, August 9th • 7:10 pm

For every ticket purchased through the Mets' Group Ticket Window, the Chapter will receive a donation. Visit www.alznyc.org for more info.

calendar of events 2006

april 25th

6th Annual Early Stage Memory Disorders Forum

april 27th

Junior Committee Gala at BLVD

may 31st

2006 "Forget-Me-Not" Gala at The Pierre

june 3rd - 6th

18th Annual Public Policy Forum in Washington, DC

august 9th

Alzheimer's Awareness Day at Shea

october 4th

19th Annual Chapter Gathering

october 22nd

Memory Walk 2006

october 31st

Mayoral Conference on Alzheimer's Disease

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2006 Forget-Me-Not Gala



Save the Date
Wednesday, May 31, 2006
The Pierre • Contact Taryn Lubin, Ext. 221

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