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New York City Chapter



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New York City Chapter

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Dear Friends,

“Democracy is not a spectator sport, it’s a participatory event. If we don’t participate, it ceases to be a democracy.” Why should anyone in the Alzheimer’s community care about participatory democracy, much less the words of filmmaker and political activist Michael Moore? I’ll tell you why.

For too long, too many members of our community have been on the sidelines watching as the number of people with Alzheimer’s has skyrocketed to more than 5 million.

The New York state budget allocates only \$1.37 million for Alzheimer’s care and support services statewide—a mere \$3.06 per person with the disease—which does little to assist individuals with the disease and their caregivers. Compared to similar states, New York is drastically underfunding these efforts. Florida and Ohio commit \$208.30 and \$204.76 respectively per person with Alzheimer’s disease

And we are silent observers as the National Institutes of Health (NIH) – an arm of the U.S. government and a major funder of scientific and medical research – provides \$2.978 billion in annual funding for HIV/AIDS research, yet only \$566 million for Alzheimer’s – while five times as many Americans have Alzheimer’s than HIV. We strongly support NIH investments in HIV, cancer and other diseases, but where is the equity for Alzheimer’s? In the almost 110 years since Alzheimer’s was discovered, we still do not have an effective therapy to cure or prevent the disease or stop its progression.

Democracy is hard. But it is our responsibility to make government work for us. I know you’re thinking that people with dementia cannot advocate for themselves, and often family members can’t either because we are overburdened with the demands of care. But unless we mobilize and make our voices heard in City Hall, Albany and on the Hill in Washington D.C., we

will never level the playing field of government’s inadequate response to the growing Alzheimer’s crisis.

There’s a role for each of us to play. It’s our job to make government leaders understand that **our** priorities are **their** priorities. Here’s what you can do:

Do your homework. Find out who your elected officials are. Use these helpful links to make your search easier: Congress (www.house.gov/representatives/find); State Legislature (www.openstates.org/find_your_legislator/); City Council (www.council.nyc.gov/html/members/members.shtml).

Learn the issues. Call the Chapter and we will give you the ABC’s of Alzheimer’s advocacy. For instance, the shocking lack of Alzheimer’s research dollars is largely a Federal problem; issues related to care, training support for homecare workers, caregiver programs and ensuring the safety of nursing homes fall under the jurisdiction of the state government in Albany; and City Council Members can provide funding for important programs like MedicAlert® + Alzheimer’s Association Safe Return®.

Gather the facts. The Chapter’s policy and government affairs experts can provide you with facts and figures, briefing sheets and other materials to help you prepare for the next step in this process.

Advocate. Going head-to-head with a respected State Senators, Assembly Members, City Council Members or Borough President can seem like a daunting prospect. But, they are



Lou-Ellen Barkan
President & CEO
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public servants; they are there to help you. And, remember, it’s your vote that keeps them in office.

The Chapter makes advocacy easy. We’ve create template letters focusing on critical issues that you can send to your elected officials (www.alznyc.org/advocate). Encourage your family members, friends, work colleagues and fellow church- or temple-goers to join you in a letter writing campaign.

Pay your representatives a visit in their local neighborhood offices. It’s important that they see you as a member of the community. Go prepared and be ready to make the case for extra funding and support. Once you tell your personal story, you’ll make an important connection. Government officials are just like everyone else. They too know someone with the disease or someone who is caring for a person with dementia. And they also care deeply about their constituents.

We know there is strength in numbers. Our annual state Rally Day unites hundreds of caregivers, service providers and members of our health care community in a major effort to affect real legislative change in Albany. This event is open to anyone who cares about the future of our community.

I hope you’ll lend your voice to our cause. Join us. You’ll become part of a family and an international movement that may one day create a world without Alzheimer’s.

Dear Readers,

Why aren't more people angry about the lack of funding for Alzheimer's care and cure? This is a disease that causes significant problems with memory and thinking before it robs one entirely of the ability to function. Alzheimer's disease is now the third leading cause of death for older adults in the United States, bringing with it an enormous burden on individuals, families, businesses and the community.

With over five million Americans and their families coping with the progressive symptoms of Alzheimer's disease (AD) and related disorders, Alzheimer's research receives less than \$600 million in federal support, which pales in comparison to other illnesses.

Yet, we know that investing in research works. Following President Nixon's "War on Cancer," investment in research increased exponentially and that investment has paid off. Many cancers are now treatable. The death rates from breast cancer and prostate cancer have decreased 6% and 2% respectively from 2000 to 2010. During the same time, the death rate from AD has increased an astounding 68%. Clearly, we need to declare a WAR on ALZHEIMER'S!!

As part of the largest and most influential Alzheimer's advocacy organization, we have taken some steps in this direction. At the federal level, we have the National Alzheimer's Plan, with the ambitious goal of preventing or effectively treating Alzheimer's by 2025. It also includes strategic plans to provide care and support for the millions of families affected. However, experts tell us we need at least \$2 billion a year to achieve that goal. How are we doing? Not good enough.

In every corner of our large and diverse state, from the rural areas upstate to the New York City metropolitan area, from those in extreme poverty to those with extraordinary wealth, families are struggling to provide the best possible

care. Currently New York State funds seven Alzheimer's Association Chapters with only \$559,000 through AlzCAP (Alzheimer's Community Assistance Program). These funds are used for outreach, education, care and support programs statewide. This year, the seven Chapters have requested an increase to \$10 million dollars to enhance the core services that provide support for caregivers.

The NYC Chapter receives very little funding from City government, aside from the support of some City Council Members, who hear directly from caregivers in their districts and know how much help they need. This year we received \$5,000 for training from Council Member Koo, and a combined \$42,250 to support MedicAlert® + Alzheimer's Association Safe Return® enrollment from Council Members Ignizio, Garodnick, Koo, Levine, and Rosenthal, and the Speaker's Pool. We are very grateful to these caring Council Members who recognize the need in their community. We can only hope that the Mayor's office takes note and follows their lead.

Last year, we partnered with the former Manhattan Borough President to conduct a New York City Caregiver Survey. The final report showed that caregivers have difficulties accessing services, even though over 40% of them spend more than 40 hours a week taking care of someone with dementia. A majority of survey respondents reported missing work to care for a relative; some missing over four full-time work weeks. NYC Caregivers are deeply displeased



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with the dementia care provided in nursing homes and hospitals. They are also frustrated with inexperienced home health aides. Consistent with the report's recommendations, we are working with our community partners to develop a comprehensive NYC strategy to address the growing impact of Alzheimer's. (You can read the full report at alznyc.org/crisisforcaregivers)

As we work to make progress in all sectors of government, we need your help to raise awareness and funds. Contact your state elected officials to request that they support increased funding for Alzheimer's care and support. Call your federal elected officials and request their support for our national legislative agenda. Drop by a City Council Member's office to tell your story to people who need your vote. It's time for Alzheimer's to come out of the closet!

Many of our readers are providing care for someone with Alzheimer's and don't have time to tie their shoes, let alone make a call to a legislator. We understand. But if you've been there and understand the demands of caregiving the isolation, the pain, the frustration, the bone-tiring tedium – please take a minute to raise your voice for those who can't.

You can learn more in this issue and read about our legislative priorities in Hillary Stuchin's article on page 12. As always, if you or anyone you know needs help, contact us

It's been a busy few months since the last installment of Chapter in the News. From the Walk to End Alzheimer's, to the New York City Marathon, and from the Junior Committee's Speakeasy Soiree fundraiser, to helping caregivers get through the holidays, New York City's press corps has had a hard time keeping up with all of the Chapter's activities!

Among the most exciting developments on the media front has been the growing popularity of Lou-Ellen's *Huffington Post* blog. If you haven't read any of her essays, we urge you to go to <http://www.huffingtonpost.com/louellen-barkan/>. Her four blogs, to date, ("The Unexpected Face of Alzheimer's;" "What Alzheimer's Caregivers Can Learn from King Lear;" "Alzheimer's, Men and Caregiving;" "Alzheimer's and the Holidays: A Survival Guide;" and her latest post: "Resolutions for Dementia Caregivers") provide important information to the Alzheimer's community and have attracted the attention of thousands on social media.

Lou-Ellen's holiday survival guide for caregivers also landed her interviews with WNBC-TV's News 4 New York at 7pm, as well as 1010 WINS radio. The interview focused on two key themes that Lou-Ellen said were invaluable to helping caregivers get through the holidays: simplify and communicate. She said that it's important for caregivers to remember that it's OK to take advantage of help that people offer to help you. She added that this is guidance that should resonate throughout the year – not just at the holidays.

The Walk to End Alzheimer's, with its record-breaking attendance of more than 7,000 people, received great coverage on television and radio. The Chapter's "Young Innovator's Award" honoree, 16-year-old high school student Kenneth Shinozuka, was a crowd favorite and a stand-out interview as he discussed his innovative invention – an electronic sensor that detects and prevents wandering in Alzheimer's and dementia patients. Also featured in media stories were Lou-Ellen, as well as award winning actors and Alzheimer's activists and Chapter supporters David Hyde Pierce and Victor Garber. Among the media outlets that covered the Walk were WCBS-TV, WPIX-TV, WABC-TV, WLNY-TV, 1010 WINS and the *New York Nonprofit Press*.

The day before the New York City Marathon, three members of the Chapter's marathon team, who ran in honor of their mothers, were profiled in *Newsday* in a story titled, "Marathoners Run for Loved Ones." Runners Dennis Finnegan Jr., Tyler Logigian and Kirsten Spillane spoke of their commitment to finding a cure for Alzheimer's and how the Chapter has been an important source of strength in their lives.

Lou-Ellen and Jed Levine continue to be called on by the media as Alzheimer's experts. When WCBS medical correspondent Dr. Max Gomez needed a source to discuss recent warnings from researchers about a possible link between benzodiazepines and Alzheimer's disease, he turned to Lou-Ellen. Similarly, *USA Today's* online resource for people over the age of 40, called *NowU*, interviewed both Lou-Ellen and Jed for a story about financial mistakes by older parents that should be warning signs to adult children that the parents may have dementia or other problems. Jed stressed how important it is for families to seek the help of an attorney who specializes in elder law when filling out powers of attorney and other legal documents.

Finally, you may have seen some familiar faces in Bill Cunningham's "Evening Hours" column in *The New York Times*, which featured the Chapter's Junior Committee gala held in September. Included in this must-read round-up of philanthropic and society events were Lou-Ellen Barkan, Liz Johnson, J.C. Hay, and Richard and Ashley Hardy. *New York Social Diary* and other society media also covered the event.

Keept looking for us in the newspapers and on TV and radio as we continue to work hard to get the news out about what the Chapter is doing to help New York's Alzheimer's community.

Advance Directives: Planning Ahead for Peace of Mind



Lou-Ellen Barkan

President & Chief Executive Officer
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Lou-Ellen Barkan (LEB): Dan, after all your years meeting with families, what are some of the most common challenges that families face as they begin to plan for their own care?

Dan Fish (DF): The biggest challenge that families face is the strong resistance to discussing this topic at all. I call it “the last taboo.” People are willing to discuss financial or very personal issues but when it comes to planning for possible incapacity, there is a very high wall. There is an almost superstitious belief that planning for the possibility of being unable to manage one’s own financial or medical decisions will cause it to occur. This is not an issue that is exclusive to older adults. A serious motor vehicle accident or sporting injury could leave someone at a very young age in the situation where they are unable to make their own decisions. Sometimes it is for a short period of time and sometimes it is permanent. Many people also resist signing these documents because they fear that they are giving up control.

LEB: What are the key documents that no family should be without?

DF: The key documents to consider are power of attorney, health care proxy and living will. The power of attorney names a person who can handle financial affairs. The health care proxy names a person to make medical decisions. The living will is a guide to the wishes of someone who is terminally ill, with no hope of recovery and for whom extraordinary services are considered, such as a ventilator or a respirator. Advance directives are more important than last wills and testaments because they affect you while you are alive.

LEB: Why do you think so many of us put off or even avoid putting these critical documents in place?

DF: These documents (often called advance directives) are quite simple to create. Some of them are available on the internet. The health care proxy’s strongest feature is its simplicity. It is only one page long. It is written in plain English. It does not require notarization. The document simply must be signed before two witnesses. The power of attorney on the other hand has become more complicated. There are many places where a mistake can be made when it is being signed. It is 13 pages long. It has multiple sections that require notarization. I suggest that these documents be drafted by an attorney because it is important to have them be signed properly. These are voluntary documents, meaning that no one can be forced to sign them. It also means that the person who is signing them must understand what they say.

LEB: Do you think the medical community has some responsibility to encourage families to prepare these documents before someone’s dementia progresses?

DF: I have found that the medical community has embraced advance directives; the health care proxy in particular. I have seen forms for health care proxies in pharmacies and in doctor’s offices. These documents must be offered to patient’s upon admission to a hospital or nursing home. In fact, the health care proxy makes life easier for the medical community. If the patient is unable to make medical decisions, the health care professional can simply look in the chart and find out who the patient appointed to make those decisions. It is a different story with financial institutions. I have found that they put up many barriers to accepting the power of attorney. Financial institutions are very concerned about their exposure to claims that they improperly allowed funds to be removed by an agent under the power of attorney. They worry that the funds may have been used improperly and that they will be subject to lawsuits.

Therefore, financial institutions may put up some road blocks. Some banks require that their own power of attorney forms be used. Some require that the power of attorney have been signed within the last six months. Some demand to see the original and will not accept a copy. Some insist upon sending the power of attorney to their legal department for review before recognizing the authority of the agent, which can lead to delays.

LEB: What happens when a family neglects to do this before someone’s dementia progresses?

DF: When a family has failed to plan in advance they may end up in court. With Alzheimer’s disease, there is a risk that the person may have progressed so far into the illness that they no longer understand the advance directives. At that point the window of opportunity has closed and the person can no longer sign the advance directives. The only available option from that point forward is guardianship. Guardianship is a full blown court proceeding that can be time consuming and expensive.

LEB: What is the best way for the Chapter to help families get this done?

DF: The Chapter can help by breaking down the barrier that surrounds talking about disability. The Chapter can help create an atmosphere where there is an open discussion of these topics.

DANIEL G. FISH is a partner in the law firm of DANIEL G. FISH, LLC whose practice is devoted to the representation of the interests of the elderly. Mr. Fish is a Past President, founding member and Fellow of the National Academy of Elder Law Attorneys. He was the Chair of the New York State Bar Association Elder Law Section and a delegate to the 1995 White House Conference on Aging

Important Documents



POWER OF ATTORNEY

A power of attorney (POA) is a written document where a person (the "principal") delegates legal authority to one or more "agents." A POA authorizes the agent(s) to act for the principal, in financial or business matters, legal matters, or other personal responsibilities. An agent must be aware that he or she is serving as a fiduciary to the principal and must act in accordance with the wishes of the principal.

While some institutions, such as banks, may inform consumers that they must use the institution's form, the general overarching form is acceptable. If there is concern around the cognitive ability of a person with dementia to sign and understand the POA, caregivers can advocate with the institution that they accept the existing form. If advance planning allows, it may behoove you to complete both a general POA as well as those from the institutions with which the person with dementia conducts business.

LIVING WILL

A living will is the most common tool used to express one's wishes around health care decisions. This document should provide a clear statement of an individual's wishes and preferences regarding medical decisions. The living will does not designate the person who makes those decisions.

HEALTH CARE PROXY

A health care proxy is a document that permits a person (the "principal") to designate an agent to direct medical treatment if the person becomes incapacitated. Health care providers and facilities must respect the authority of the agent and any wishes of the principal stated in a health care proxy. It may be necessary for an agent to have to advocate with health care professionals in order to ensure the principal's wishes are known and respected. In order to do so most effectively, it is essential that the principal clearly express to the agent his or her wishes around the types of care he or she wants and does not want, and the ways in which he or she wish their care to be provided.

To learn more about these tools, and more, attend the Chapter's Legal & Financial Seminar. For upcoming dates and to register, call our **24-hour Helpline at 800-272-3900.**

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I'm not a scientist. I'm a caregiver.
And I'm helping to find new Alzheimer's treatments.

alz.org/trialmatch

Michael M.
Care partner to his wife
Paula M. M.

alzheimer's association
trialmatch

I lost my mother to the disease a few years ago, and watched my father struggle with her care. It seems to me that more and more people have developed Alzheimer's disease throughout the years but services for these people are lacking. I recently found out that the day center my mother used to go to two days a week has closed. I feel like more needs to be done around advocacy; our elected officials need to know that more is needed for people with Alzheimer's disease. I would like to get more deeply involved. What can I do?

- Brenda



Stephanie Aragon
Manager, Helpline
Helpline@alznyc.org

Dear Brenda,

Thank you for contacting us about opportunities to help with the fight against Alzheimer's disease. There are many people who feel the same way as you, that more is needed for people with Alzheimer's disease.

I bet you have asked yourself: What are some changes I would like to see made? How can I help to improve the lives of people with the disease? Here is the answer: Become an Alzheimer's advocate!

Do you believe additional day care centers specializing in dementia care should be made available to people living with Alzheimer's disease? Become an Alzheimer's advocate!

Do you believe nursing homes should have specialized units for the memory-impaired that offer high quality care using up-to-date methods? Become an Alzheimer's advocate!

Do you believe that neighborhood resources such as museums and botanical gardens should offer special programs for people suffering from dementia? Become an Alzheimer's advocate!

It takes one person to initiate change; why not become that person?

Become an Alzheimer's advocate and play an important role in improving the quality of care and quality of life for people with Alzheimer's disease and their families. Help us elevate this issue from a disease to a cause. When you advocate, you actively support a cause that's important to you, such as Alzheimer's disease, and you share your feelings about this cause with public officials.

Many people believe that advocating requires special training or an extensive time commitment, but that

**It takes one person
to initiate change;
why not become
that person?**

**Visit
alznyc.org/advocate**

is not necessarily the case when you become an Alzheimer's advocate. You don't need to be skilled in politics to be an advocate! Even if you have a demanding schedule, go to work and/or school, or are raising a family, there are many different ways you can lend your voice to achieve our vision of creating a world without Alzheimer's disease.

Alzheimer's advocates raise awareness

about the needs and rights of people with Alzheimer's disease and their families as well as urge government officials to support research and care. Becoming an Alzheimer's advocate could not be easier. All you need to do is:

1. Visit our website at www.alznyc.org/advocate.
2. Once there, click on the purple box labeled "Become an Advocate."
3. Enter your information and hit submit.

You then join the thousands of Alzheimer's Advocates nationwide who are already helping raise awareness of our cause.

Make sure you check your email regularly because we will keep you up-to-date on advocacy issues and will contact you when there are opportunities to participate in grassroots advocacy activities. We will also send out Action Alerts when we need your help to contact your elected officials. The Action Alert email will tell you which government officials need to be contacted and how to contact them. We will even provide wording on what you can say.

You can also be a more active Alzheimer's advocate by attending one of your Town Hall Meetings or telling your personal story about your mother to your elected officials.

Visit www.alznyc.org/advocate to learn more and to sign up.

My mother has 12 hours of home care per day. This is a lifesaver. I recently found a letter from the Department of Health in her mail. The letter talks about Medicare and Medicaid, and something called "FIDA." I do not know the difference between Medicare and Medicaid. I think my mother has both. There was also a letter from her health insurance plan about something called a "FIDA plan." What do these letters mean?

- Stressed Out in Sunnyside (SOS)

Dear SOS,

You and your mother **MUST** take action and answer the letters that you found. If you do nothing, your mother's health insurance will soon change automatically. She has the right to opt out of this change before it happens. This may not be clear from the notice.

Your mother is probably enrolled in a Managed Long Term Care plan ("MLTC plan") for her home care. There are 25 companies that offer these plans in New York City. Most of these companies now offer a new type of health insurance called a Fully-Integrated Dual Advantage plan ("FIDA plan"). A FIDA plan combines all Medicare and Medicaid benefits into one plan.

To review, Medicare and Medicaid are two different types of health insurance. Medicare insures most senior citizens and many people with disabilities. Medicaid insures people who have limited finances. Medicaid also pays for long-term care. Medicare does not pay for long-term care, so people who need home care often have both types of insurance.

Most New Yorkers who have Medicare and Medicaid, and who need home care, must now be enrolled in an MLTC plan. MLTC plans pay for some Medicaid benefits, including home care. MLTC plans do not pay for primary doctors, or major specialists like cardiologists, neurologists, oncologists, or ophthalmologists. These doctors are paid for by Medicare. Multiple insurers means

multiple insurance cards and multiple appeals processes when a health benefit is denied or reduced. This creates a maze even for advocates!

In a FIDA plan, your mother will use one card for all of her care needs. She will appeal to a single plan for problems with her care. She will have no copayments, no deductibles, and no premiums to pay. She and her doctor, among others, will also sit on an "interdisciplinary team" that will plan and coordinate her care. She will remain responsible for payment of her Medicaid surplus in a FIDA plan. Your mother can disenroll from FIDA at any time and return to her previous health insurance coverage.

If you and your mother agree that FIDA is right for her, you should compare plans. Switching to a FIDA plan is like switching to a new insurer. This is true regardless of which company offers the FIDA plan — even if it is the same company that offers her MLTC plan.

You do not want to interrupt ongoing care, including longstanding relationships with doctors, or current treatment. If you changed jobs, wouldn't you want to check whether each of your doctors and prescription drugs were covered under your new employer's health plan? The same reasoning applies in your mother's case.

By law, your mother must continue to receive the same services for the first 90 days after her enrollment in any FIDA plan. After day 90 she may not be able to see the same doctors and take the same medications. This

could mean big bills! You owe it to your mother to ask the plans you are considering for information. Request provider networks and drug formularies. These are directories of doctors, services, and medications that the plans cover. Make sure that each doctor she sees, and each medication she takes, is covered!

Your mother will be enrolled in a FIDA plan automatically if she does nothing. She will likely be enrolled in a FIDA plan offered by the same company that administers her MLTC plan. Her current coverage will stay the same if she opts out. She can opt out by calling New York Medicaid Choice at 1-855-600-3432.

*By: Peter Travitsky
New York Legal Assistance Group*

For free information and advocacy on MLTC or FIDA, call the Independent Consumer Advocacy Network ("ICAN") at 1-844-614-8800 for assistance. ICAN is not affiliated with a health plan.

For a free caregiver fact sheet on FIDA, visit <http://www.wnyc.com/health/download/522/>

To learn more about these significant changes to New York's Medicare and Medicaid program, join us at our monthly education meeting on March 9 at 6pm. To register, call our 24-hour Helpline or email us at helpline@alznyc.org.

Family Caregiver Workshop



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When family members enter the room for the first session of a Family Caregiver Workshop (FCW), I often have music playing in the background. I do this because people tend to come in carrying a lot of negative emotions: stress, anxiety, sadness, or guilt. The emotions are real and very understandable, but they can also be overwhelming. The music is there to lighten the mood and set the tone for a group in which we try to encourage them to think about their caregiving situations with a touch of objectivity.

The problem with ignoring the elephant in the room is that eventually the disease progression demands that we pay attention, and we don't want to wait until there is a crisis to do so.

It is incredibly difficult to be objective while witnessing the decline of a mother, father, or spouse or partner, but it is sometimes essential to do so in order to learn. Nobody chooses to be in this position, and most people don't want to talk about it. It's like the classic idiom of the "elephant in the room." Dementia is a problem that is so big it cannot be ignored forever,

and yet most people would prefer to pretend that it does not exist. The problem with ignoring the elephant in the room is that eventually the disease progression demands that we pay attention, and we don't want to wait until there is a crisis to do so.

The FCW is a 10-hour training offered in both English and Spanish. Workshops take place in The Dorene Scolnic Education and Training Center at the Chapter office, as well as at community-based organizations in Brooklyn, Queens and the Bronx, and on Staten Island in the near future.

Thanks to the Chapter's expansion in 2013, we are now able to provide specialized groups as well, such as workshops for spouses and partners of persons with dementia (PWD's), and workshops for caregivers of early-stage individuals. The FCW provides family caregivers with practical tools to manage the interpersonal aspects of dementia care. Through lecture, discussion, and interactive exercises, we examine the changes that are happening in the brains of PWDs. We try to imagine what the world looks and feels like to them, and how this may affect their communication and behavior. We then begin to identify ways that caregivers can adapt in order to decrease friction in the caregiving relationship, meet safety needs, and improve the quality of life of everyone involved.

The essence of the FCW lies in the presumption that in order for meaningful change to happen, the caregivers must be the ones to adapt. The expectation that the PWD will be able to change is unrealistic. There is a tremendous shift in perspective that often takes place over time, during which caregivers must go through a process of re-defining and re-establishing their relationship with the PWD in the context of this chronic, degenerative condition. Caregivers also need to learn emotional coping techniques and to cultivate a practice of self-care, so that they

meet their own needs while also adapting to the needs of the PWD.

The FCW arms caregivers with a general road map of the disease process as well as with the knowledge that each PWD is unique in terms of needs, strengths, personality, preferences, and personal history. We present a variety of concepts and tools, and invite caregivers to enter into a trial and error process. What works for one person may not work for another, just as what works for someone one day may not work as well the following day. The more tools caregivers have in their toolboxes, the better equipped they are to deal with the ups and downs of dementia. There are no easy answers, but we can provide some guideposts to consider as caregivers navigate this journey.

It sometimes comes as a surprise to people when I tell them that there is a lot of laughter in my groups. Finding humor, being realistic, being sad, being hopeful, being connected to the PWD in a meaningful way – all of these themes tend to come up in the workshop. Caregivers often realize, following this experience, that they want to attend an ongoing support group. Others go on to develop relationships with one of our Care Consultants, or to attend other educational programs like our Legal & Financial Seminar.

For a more detailed description of the workshop content, please refer to our updated Family Caregiver Guide, available on our website at www.alznyc.org/fcg. You may also call our 24-hour Helpline at 800-272-3900 to request a copy of the Guide or to register for an upcoming FCW session. You can also refer to our Education Calendar on page 30 for upcoming dates.

A Day to Gather, Connect and Laugh



Lara Green
Manager, Early Stage Services
LGreen@alzny.org

For Early Stage Services clients and staff alike, it is always one of our favorite days of the year; on November 7, we hosted our 4th Annual Gathering for People with Early-Stage Memory Disorders. This is a unique conference for people with a diagnosis of early-stage dementia to come together and meet new people, share experiences about living with their illness, learn from each other, and of course have some fun! The Gathering is solely for early-stage clients and does not include their care partners, which is part of what makes it so special.

In past years, the Gathering has included sessions on using faith and humor to cope with Alzheimer's disease, music as a means for improving mood and overall well-being, and even collectively writing a letter to Congress advocating for increased funding for dementia research. The sessions at this year's event proved to be equally stimulating and entertaining.

The day started with a light breakfast and a warm welcome from



Concerts in Motion's jazz trio performance of New York, New York. (Vocals: Faith Roberson, Keyboard: Etsuko Tajima, Bass: Nori Naraoka)

Lou-Ellen Barkan, Chapter President and CEO. The morning session, entitled "Here's Your Chance!" featured Dr. Lisa Ravdin, Director of the Neuropsychology Service at Weill Cornell Memory Disorders Program, who provided a brief and informative medical overview followed by a lengthy question and answer session. We often hear from our clients that they do not get the chance to ask their doctors important questions, either due to time constraints, infrequent visits, or because their care partners do most of the asking. Sometimes clients share that their questions are not answered directly, or in a way that is sensitive to their needs. "Here's Your Chance!" provided our clients with

the opportunity to have a candid discussion with a knowledgeable professional in the field. They asked their own questions about what matters to them, not those of their families and care partners. Thoughtful inquiries about genetics, research, symptoms, stigma, and disease

progression all came up. Dr. Ravdin stressed the importance of maintaining a healthy lifestyle in the early stage of

dementia, including staying physically, mentally, and socially active.

During a lovely catered lunch, the 31 early-stage clients in attendance enjoyed mingling with one another. The lunch was the highlight of the day. Not only was the food great, but we heard vibrant conversation and eruptions of laughter pouring out of the room, which was really what the day is intended to be about – people connecting with one another. In the afternoon, we lightened things up with a New York-themed musical performance provided by Concerts in Motion, of course accompanied by traditional New York-themed desserts! Concerts in Motion is a non-profit organization that provides professional concerts to people who might otherwise not have access to quality live music, such as local senior centers, hospitals, and nursing homes. We were pleased to partner with them. They set us up with a fabulous jazz trio who played everything from popular Broadway show tunes, to Sinatra, to a unique rendition of The Beatles song, "Blackbird."

All in all, it was a great day and another successful Gathering. Everyone left in great spirits, and we are already getting asked about what is on the agenda for next year's event.



Dr. Lisa Ravdin, Director of the Weill Cornell Neuropsychology Service, facilitating an engaging discussion on memory loss.

Local Politics Matter

Local and state governments deeply influence our day-to-day lives. A phrase associated with former Speaker of the House, Tip O'Neill, "All politics is local," ties a politician's success to his or her understanding of the issues directly affecting their constituents and communities. Because of this focus on local issues—the issues that might matter most to you—everyone should know who represents them as their voice at all levels of government.

In New York, the Governor's Office, State Legislature, New York City Mayor's Office, and New York City Council pass laws, enact policy, and establish budgets of their own to make sure New York as a whole is active in its legislative and policy initiatives, which includes (a very small amount of) funding and support for Alzheimer's disease and related dementias. Looking at these budgets — New York City has a budget of nearly \$70 billion and New York State's budget is in excess of \$140 billion — the small amount of funding allocated to Alzheimer's disease care and support by each is concerning.

Currently, New York State funding for the Alzheimer's Community Assistance Program (AlzCAP) is an embarrassing \$559,000 — or just \$1.75 per person with Alzheimer's disease or related dementias. Funding for this program is split between the seven Alzheimer's Association Chapters in the state for outreach, education, care and support resources, watering down its potential impact even more. While there is an additional \$811,000 allocated for other statewide Alzheimer's services, when compared to other disease-related causes funded by New York State — HIV/AIDS and cancer received more than \$144 million and more than \$133 million respectively — the disparity in funding is overwhelming. This year the New York State Coalition of Alzheimer's Association Chapters

is requesting \$10 million for the AlzCAP program, plus an additional \$5 million for a statewide awareness campaign. With more funding each Chapter will be able to extend their reach and help substantially more New Yorkers living with or caring for a person with Alzheimer's disease.

Funding from the New York City Government is no better. This year we received just \$47,250 from the discretionary funds of City Council Members who are aware of the impact Alzheimer's disease has on their communities. Those who channeled funding to the Chapter often hear directly from their constituents affected by Alzheimer's and respond accordingly. While the amount of money allocated to the NYC Chapter is small, it is proof that local outreach and involvement influences elected officials.

The New York City Chapter is one of the few Alzheimer's Association chapters nationwide that commits full-time staff to public policy and advocacy efforts. This is in large part because we work with 65 New York State Assemblymembers, 26 State Senators, and 51 City Council members, plus Borough Presidents and the Mayor's office. We also interface with 11 members of the House of Representatives and two Senators. In our meetings with legislators, our requests are met with general support, but elected officials listen to their constituents. If New York City residents affected by Alzheimer's disease contacted the Governor's office, the Mayor's office, their City Council Member, State Assemblymember, and State Senator demanding increased funding and support services, then lawmakers would be further obligated to make changes in how New York approaches this public health crisis.

I recently asked a State Assemblymember why it's so important for the public to know

their local representatives and stay informed of issues affecting their communities. His reply was simply, "Because local government is where things really happen." And he is right. Elected officials are accessible to their constituents. They are the local problem solvers. As Alzheimer's advocates, we must use this access to our advantage. Our legislators need to know that more must be done for those living with or caring for a person with Alzheimer's disease or other forms of dementia. Call, email, write a letter, or use social media to reach out to your State Senator, Assemblymember, and City Council Member. Let them know how Alzheimer's disease is impacting your family. Let them know that there are more than 380,000 people living with Alzheimer's disease or related dementias in New York State — an estimated 250,000 live in New York City! Let them know that this disease is already impacting our state's economy. Let them know that those affected by the disease cost New York State 19 times more than the average Medicaid recipient, and that more than 1 million New Yorkers provide 1.15 billion hours of unpaid care and support annually for people with dementia. Let your local legislator know that with the number of individuals living with or caring for a person with Alzheimer's disease set to rise in the coming years, something must be done.



PASSED

alzheimer's accountability act

\$25 million increase for alzheimer's research

You did it!

Thanks to the hard work of Alzheimer's advocates, the Alzheimer's Accountability Act was fully incorporated into the recently signed funding bill. The bill includes a **\$25 million** increase for Alzheimer's research.

With your help, we've reached another milestone in the fight against Alzheimer's, but there's still more to do!

**Become an advocate
and join the fight today.
Let's #ENDALZ!**

What it means to be an Alzheimer's Advocate and Ambassador



Hillary Stuchin
Director of Public Policy
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I began volunteering with the Alzheimer's Association, New York City Chapter in 2012 as a member of the Speaker's Bureau. Through this program, I was specially-trained by the NYC Chapter to deliver presentations on Alzheimer's disease and local programs and services to audiences including senior centers, community organizations, clubs, congregations, schools, and other groups.

As I was making these presentations, I was directly experiencing what it's like to have a family member, my mother, living with Alzheimer's disease. This drove me to do to want to do more, and to ask myself, "What's the most I can do — aside from becoming a scientist (I'm an actor) — to make a difference and end Alzheimer's disease?" I wanted to practice what I preached when speaking before others interested in our cause.

Becoming an Alzheimer's Association Ambassador to my representative in Congress was the answer. This seemed to be the best way to convey the impact of Alzheimer's disease to someone who's in a position to impact national policy, and reward these efforts with real action.

I have found first-hand that advocacy works and our efforts are met with a positive and often personal response. My Congressional Representative, Yvette Clarke (NY-9) supports Alzheimer's research as well as support systems for Alzheimer's caregivers. Additionally, she is a strong supporter of funding for the National Institutes of Health (NIH). On a personal note, Congresswoman Clarke wrote me a letter right after my mother died from Alzheimer's in the fall of 2013. On the same day, I received an email from Congresswoman Clarke's Senior Health Policy Advisor informing me that Rep. Clarke

would co-sponsor The Health Outcomes, Planning, and Education (HOPE) for Alzheimer's Act.

Like so many things run so capably by the Alzheimer's Association, when you are an Alzheimer's Ambassador, you are not alone in your work. Though Ambassadors respond on the federal level, I have also joined the NYC Chapter in their work with the New York State Legislature. For me, being an Ambassador has been like having the best possible crash course in public policy both in Albany and in Washington, D.C. From the New York City Chapter's journey to their annual Albany Rally Day, to the incredibly pivotal annual Advocacy Forum in D.C., as an Ambassador I've been offered a free education in how to share my family's experience of Alzheimer's with those in a position to effect better policies and invest in research.

The Ambassador program is structured very well to telescope from local interaction with district staff to a broad view of the national landscape in Washington, D.C. at the annual Alzheimer's Advocacy Forum. This event culminates in Capitol Hill Day, allowing one to see first-hand how anyone can have an impact on decision-makers when the cause is powerful and the organization is good. It's moving to see people affected by Alzheimer's tell their stories in Congressional offices. Members of Congress and their staff can often relate to the experience of caring for a family member or friend with Alzheimer's, and in the presence of a surviving spouse or caregiver telling their story of fending off Alzheimer's disease, the most powerful lawmakers in the country visibly soften. That's how you know that private grief can be transformed into public impact. Being an Ambassador leaves me gratified.

It is so important to advocate for change in our country's approach to Alzheimer's disease no matter what your political stance. With a non-

partisan issue like Alzheimer's, one sees a better side of Washington. On the other hand, in a savage disease like Alzheimer's, politics becomes personal. The political will to support the Alzheimer's cause is not the same thing when it comes to supporting funding of Alzheimer's research. That's where an Ambassador needs to be as much a fighter as a diplomat. We all need to make this goodwill translate into better funding of Alzheimer's disease research.

There are signs that Alzheimer's is becoming a national priority, as a result of the tireless volunteer and professional advocacy brought to bear by the Alzheimer's Association. To strengthen these efforts and get politicians to respond, we need more Alzheimer's advocates. I encourage anyone looking for real change in Alzheimer's disease research and policy to become an advocate or join an Ambassador team, and tell your story to all your elected officials. Never hide from Alzheimer's.

As a volunteer with the Alzheimer's Association, New York City Chapter, Craig Colfelt has worked with us in a variety of ways, helping to raise awareness and funds. Below he details some of his most important work and experiences as an Alzheimer's Association Ambassador.

The New York Mets logo, featuring the word "Mets" in a stylized blue script font with a red outline, set against a white background with a red and blue striped pattern.

ALZHEIMER'S AWARENESS NIGHT

Friday, June 26, 2015



@ Citi Field
BUY TICKETS
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FIELD BOX \$53 | PROMENADE BOX \$20
FREE T-SHIRT WITH EVERY TICKET PURCHASE!

The New York Mets invite you to Citi Field for the 12th annual
Alzheimer's Awareness Night!

Cheer for the Mets while you support the leading voluntary health
organization in Alzheimer's care, support and research.



Carol Berne

Senior Vice President of Development,
Director of Leadership Giving
CBerne@alzny.org

I am delighted to begin this report by thanking all the donors to our 2014 Year-End Campaign. As of this writing we are at \$486,000 towards our \$500,000 goal with 960 donors, of which 262 are new. Our Board of Directors has also stepped up to the plate with ____% participation, and they in turn have raised \$166,619 or 36% of the total. Thus far, we are tracking 27% ahead of last year. Thank you.

What makes this campaign special are the thoughtful notes that accompany the donations. They are a reminder of both the sadness of Alzheimer's and the resilience of caregivers. They are also a tribute to the generosity of our clients, who understand the importance of what we do, and wish to give back for the help they've received. Many donors wish to honor a loved one or recognize a NYC Chapter staff member who helped them along the way.

Highlights include a \$20,000 gift from a member of our support group, a \$5,000 gift from a longtime Support Group Leader, and a \$10,000 gift from a daughter who cared for her mother many years ago, and remembered the outstanding support she received from the NYC Chapter. The following note from a current support group member expresses this sentiment best, "Thank you for the peace that my support group brings me and thank you to the generosity of the New York City Chapter."

In addition to individual gifts for our year-end campaign we also received substantive support from foundations over the last few months. The New

York Community Trust and The Jean and Louis Dreyfus Foundation, Inc. are directing their support to our Dementia Care Training Program for Professional Caregivers. We train, in English and Spanish, over 300 home care workers annually to become skilled in good dementia care, benefiting both a family who needs caregiving assistance as well as the aide by providing stable employment. And with our recently launched dementiaaides.org, we are helping to make these matches possible. All free of charge.

The Warner Foundation, Inc. continued its leadership support of our MedicAlert® + Alzheimer's Association Safe Return® Program (MASR) for wanderers and our Early Stage Services. With over 22,000 New Yorkers enrolled in this life-saving program, this year we will be streamlining operations and computerizing much of the data we store. We will have the most up to date information quickly available to improve efficiency and enhance the safe return of a missing person with dementia who wanders. The Charles and Mildred Schnurmacher Foundation, Inc. has added its support to MASR to cover enrollment and outreach. The PARC Foundation, Inc., continues its outstanding support of our innovative Palliative Care initiative and the Faith Home Foundation continues its support of our Brooklyn expansion.

I wish I could recognize all donors, but space precludes. Please know how valuable you are to us and to the over 265,000 New Yorkers living with Alzheimer's disease. As always, if you would like more information on how you can support our work, and keep our programs free of charge, please contact me. Thank you.

Know Your Charity

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

American Health Assistance Foundation
Alzheimer's Foundation of America (AFA)
Long Island Alzheimer's Foundation (LIAF)
Staten Island Alzheimer's Foundation (SIAF)
Alzheimer's Disease Resource Center (ADRC)

Ways to Give

Giving by Check

Please make checks payable to the Alzheimer's Association, New York City Chapter. For your convenience, a self-addressed postage paid envelope has been provided in this newsletter.

Online/Credit Card

Visit www.alz.org/nyc and click on *Donate* or call 646-744-2908 or 2927. We accept MasterCard, Visa and American Express.

Appreciated Securities

Gifts such as stocks or bonds may offer substantial tax advantages. 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 those affected by Alzheimer's disease. Your bequest may have estate tax planning benefits as well. The following is sample bequest language for discussion with your attorney:

I, _____ (first and last name, city, state, zip), give, devise and bequeath to the Alzheimer's Association, New York City Chapter, with offices located at 360 Lexington Avenue, 4th Floor, New York, New York 10017, (insert written amount of gift, percentage of the estate, or residuary of estate, or description of property) to be used for (insert "its unrestricted use" or name of NYC Chapter program or research program.)

Life Insurance and Retirement Plans

The Alzheimer's Association, New York City Chapter can be named a beneficiary of your retirement plan or insurance policy.

Donor Advised Funds

If you have established a Donor Advised Fund through another organization (e.g., Community Foundation, investment firm) you may recommend the award of a grant to the NYC Chapter. Please check the guidelines pertaining to your Donor Advised Fund.

Corporate Giving

Payroll deductions, matching gifts, and event sponsorships are ways to support the Chapter.

Please note that gifts and bequests made by NYC donors are shared between the NYC Chapter and the National Alzheimer's Association unless the donor specifically requests that the gift be restricted for research or for a New York City Chapter program.

Please contact Carol Berne, Senior Vice President of Development, Director of Leadership Giving, at 646-744-2905 or CBerne@alzny.org if you would like additional information.



The Alzheimer's Association, New York City Chapter meets the Better Business Bureau Wise Giving Alliance Standards for Charity Accountability.

The 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.

In Memoriam

The Association Mourns the Loss of Founder Jerry Stone



Founding President and
Honorary Chair of the
Alzheimer's Association
1913 - 2015

The Alzheimer's Association has lost our Founding President and Honorary Chair, Jerome H. Stone. He was not only a longtime board member, volunteer and advocate, but also a philanthropist who led by example and believed deeply in giving

to transform our cause. Mr. Stone was a true visionary in the Alzheimer's movement. When his wife, Evelyn, was diagnosed with the disease in 1970, he recognized the need for a leader in the field that would unite caregivers, provide support to those facing Alzheimer's, and advance research toward treatment, prevention and, ultimately, a cure. His drive and determination led to the creation of the Alzheimer's

Association in 1979. Mr. Stone is responsible for where we are today in the fight against Alzheimer's. He took a disease that was cloaked in silence and helped to create a national — and global — conversation. He meant so much to the many who are invested in this cause. We honor his memory and continue his legacy by moving forward to achieve our vision of a world without Alzheimer's.

Jeffrey Jones - Portrait of a Leader



Lou-Ellen Barkan
President & Chief Executive Officer
LBarkan@alzny.org

Lou-Ellen Barkan (LEB): What brought you to the Alzheimer's Association?

Jeff Jones (JJ): It's a great story. I'm a partner at KPMG and got a call one day asking me whether I was interested in joining the Board of another charity here in New York. One of my partners had to leave the Board because of term limits and wanted to know if I wanted to take his spot. I was interested in joining a Board to give back to the community but really had no affinity for that particular organization. The person at my firm that was helping with this asked what I would be more interested in. I said the Alzheimer's Association. When we called to inquire, you said "Send him over."

And when we actually met, it became really clear to me really quickly that this was going to be a good fit for me.

I was interested in the Association because this disease has affected my family. On my mother's side, both of her parents had the disease. My grandfather died from the disease in the early 1970s. I was too young to have ever really known him when

he wasn't ill since he died when I was about 5 years old. But I do very vividly remember noticing, even as a 5 year old, that something was not right because he was not able to be independent like all other adults. Of course, I didn't understand why. And then about 10 years later, we started to notice that my grandmother was starting to have memory problems which we watched progress over the next 10 years or so. By that time I was a teenager and could understand completely what was going on. Both



of those experiences were profound for me in different ways and made me want to get involved with the Alzheimer's Association.

LEB: What are some things that have changed since you first became a Board member?

JJ: The biggest change that I have seen is the growth in the Chapter. When I first joined the Board, in

Manhattan we occupied about 25% of the space we have today and we had no space in the boroughs. We were extremely fortunate to receive some large gifts that have allowed us to double the Manhattan space – twice – during my tenure and expand to have operations in Brooklyn and Queens. That is extremely gratifying to me because it gives us the ability to serve the community.

LEB: Would you tell us something about yourself?

JJ: I was born and raised in the Baltimore suburbs and attended Loyola College in downtown Baltimore. After graduation, I joined KPMG in Baltimore. In 1994, I came to New York for what was supposed to be a two-year rotational assignment in our National office. But then life happened. The two-year assignment

extended into a third year; I met my partner; and I applied for a two-year fellowship at the Securities and Exchange Commission down in Washington, DC. After that I came back to New York for what was again supposed to be another two years. Life kept happening and that got extended a few more times. So I find myself still here 15 years later. I've really become a New Yorker and can't imagine being anywhere else.

LEB: We're obviously in the care business. Although, we care about curing the disease, the day-to-day work here is done all in the area of care. How do you feel about the balance between care and cure?

JJ: Before joining the Board, I really did not understand the difference between the New York City Chapter and the National Alzheimer's Association, and specifically how each organization divides up the overall mission of the Association. Of course, each part of those missions is absolutely critical to our success in fighting this disease in the long run whether it is raising concern and awareness nationally, getting federal support for Alzheimer's research and developing and implementing the Federal National Alzheimer's plan. I'm so glad that we have the National Alzheimer's Association in Chicago to lead the charge on those matters.

But what really resonated with me when I first got involved was the Chapter's focus on caregiving. I think it was the experience with my grandmother's course through the disease that makes me so passionate about getting people access to the right care. My grandmother was diagnosed with the disease in the early 1980's and my family had no idea that the Alzheimer's Association existed. The caregiving burden fell mostly to my mother and her sister. I know they were doing the best they could with no resources or guidance and I know now that some mistakes were made. The foundation of the caregiving model was to keep my grandmother out of a nursing home for as long as possible. That is a great goal. But caregiving when you know what you are doing is stressful. When you don't really know what you are doing, it borders on intolerable. So the solution was to shuttle my grandmother back and forth between the two homes. For a person



that was suffering from memory decline, that must have been terribly confusing. The other thing I remember about that time is how tense it was in our house when it was our turn to care for my grandmother and to be perfectly honest, how relieved I felt when our turn was over – not to mention how guilty I felt for thinking those thoughts. I was only a teenager so I can't even begin to understand how stressful all of this was for my grandmother, my mother and her sister.

That's kind of a long way of telling the story, but it really is the foundation for why I got involved in the Alzheimer's Association and why I became so deeply involved on the Board at the Chapter level.

For as long as there isn't a cure for this disease, I've heard our social workers say over and over that the best treatment for someone is good care. I really believe that. The resources that the Chapter provides to help people deal with the day-to-day and night-to-night trials and tribulations of caring for someone with Alzheimer's is so important to changing an intolerable task into a manageable one. We see it all the time in the cards and letters that people send in praising the Chapter's staff. They are a true lifeline to people dealing with this disease. I applaud them and it makes me proud to be leading the efforts to make it possible for them to do what they do.



Annual Meeting — Early Diagnostic Tools and Prevention Studies

By James Campbell

The Alzheimer's Association, New York City Chapter brings together the top minds in the fight against Alzheimer's to discuss research and insights in an intellectual yet accessible manner. The 27th Annual Chapter Meeting, "Early Diagnostic Tools and Prevention Studies: New Hope in the Global Fight Against Alzheimer's" continued the tradition with record-setting attendance.

Chapter President and CEO, Lou-Ellen Barkan, commenced the event by delving into her experience with the NYC Chapter and her struggles with her father's Alzheimer's diagnosis. In doing so, she introduced the event's theme: sustaining bridges between the personal and the scientific while advancing diagnostic and preventive tools.

Award-winning journalist Dr. Max Gomez, who guided the evening's conversation with thoughtful questions and astute commentary, introduced the distinguished panel: Dr. Mary Sano, Professor of Psychiatry and Director of Research and Development at the James J. Peters VA Medical Center; Dr. Ralph Nixon, Professor of Psychiatry and Cell Biology at NYU Langone Medical Center; and Dr. Richard Mayeux, Professor of

Neurology, Psychiatry and Epidemiology at Columbia University.

The speakers began by discussing their recent research. Dr. Sano is currently involved in the A4 study, which identifies cognitively intact older people with accumulations of proteins thought to cause Alzheimer's symptoms. The study's scientists hope to stabilize memory and cognition levels by removing these accumulations. Dr.

Nixon considers aging and lifestyle as he examines why these accumulations initially form. Dr. Mayeux endeavors to unscramble the Alzheimer's genetic puzzle by studying patients' families.

Dr. Gomez continued the discussion by asking the question on everyone's mind: "Can we prevent Alzheimer's?" Because prevention is not presently possible, Dr. Sano cited the Chapter's call for individuals to "treat their treatable conditions" and manage stress, obesity and cardiac risk factors. Preventive measures can only be developed through further research, which requires volunteers. Dr. Gomez

is intimately familiar with the importance of research subjects; his father, an Alzheimer's patient, donated his brain to NYU. Dr. Sano also stressed the importance of supporting loved ones who want to participate in research.

As the evening wound down, the conversation turned to public policy. Dr. Sano highlighted funding deficiencies, saying Alzheimer's is "the second most feared disease in the world, but



(From left) Moderator, Dr. Max Gomez, facilitates the conversation between panelists, Drs. Mary Sano, Ralph Nixon and Richard Mayeux.

certainly not the second most funded." Dr. Mayeux also addressed the decline in federal funding, noting that thirty years ago "20% of submitted grants were funded. It is now 8%." Dr. Nixon applauded the Chapter's support for the National Alzheimer's Project Act, which mandated that the government respond to the growing Alzheimer's epidemic. However, the Act still lacks teeth and he implored the audience to contact their Senators and Representatives in Congress.

Jed Levine, the NYC Chapter's Executive Vice President, Director of Programs & Services, concluded the evening by driving home the fact that battling Alzheimer's requires support from all walks of life. "In the spirit of hope for the future," he introduced the 2014 Alzheimer's Association Research Grantees: Dongming Cai, Elizabeth Guerro-Berroa, and Roger Lefort. Finally, he reiterated the audience's personal responsibility, asking them to act as advocates and directing volunteers to the Association's TrialMatch® website, because "there is no future for research without funding or without subjects."

If you missed the event, you can watch a video of the presentations at https://www.youtube.com/watch?v=tAQUz_s4j5I.



Lou-Ellen Barkan, NYC Chapter President & CEO and Jed Levine, Executive Vice President and Director of Programs and Services are joined by the panelists of the 27th Annual Meeting, and recipients of 2014 Alzheimer's Association Research Grants. (From Left: Roger Lefort, Dongming Cai, Max Gomez, Lou-Ellen Barkan, Jed Levine, Mary Sano, Richard Mayeux, Elizabeth Guerrero-Berroa, and Ralph Nixon)

The Betty Gutttag Support Group Room



On Thursday evening, October 23, we celebrated the dedication of The Betty Gutttag Support Group Room on our third floor Program Center. Marking this special occasion was Board co-chair Stephen Casper and family. Peggy Casper and her brother Robert Gutttag named the Support Group Room in honor of their mother.

The Chapter's support group program helps caregivers maintain their own health and resilience by providing a safe place where they can share their feelings and not feel alone. The NYC Chapter has over 120 support groups held at the chapter and throughout the five boroughs with over 700 support group members.



(Left to right: Robert Gutttag, Dorie, Peggy, Jackie, and Stephen Casper)

The Alzheimer's Association, New York City Chapter invites you to the Charles Evans Annual Lecture on the Art and Science of Caregiving

A Place Beyond Words: The Literature of Alzheimer's

Wednesday, May 6, 2015

The Times Center
242 West 41st Street (between 7th & 8th Avenues),
New York City

RSVP by April 28, 2015

For more information, contact
Crissy Vicendese at 646-744-2927 or

www.alznyc.org/CaregivingLecture



This Event is Free of Charge.

It Takes a Village

By David S. Duplay
Founder and CEO, healtheo360

How do you cope with Alzheimer's disease? For the over 5 million visitors on healtheo360, sharing stories is remarkably helpful. Whether one is living with or caring for someone with Alzheimer's, it is good therapy to see hope through the stories of others and to share one's own story. I know all too well how important hearing from others can be, as my own mother suffers from Alzheimer's.

healtheo360 is an online caring community for people with chronic conditions and caregivers. The community has a wide range of supported conditions in addition to their large population of Alzheimer's patients and caregivers. Membership in healtheo360 is 100% FREE and never solicits donations of any kind.

Caregivers can suffer burnout, so it's important to take care of

yourself too. Don't ignore the signs of caregiver stress or depression. Understandably, sometimes it can feel like no one recognizes all the work you do or that you might feel isolated and lonely. At healtheo360, you can share your stories through journal entries or video testimonials and receive support from others just like you. Other Alzheimer's patients and caregivers have walked the same path and know exactly how you are feeling.

Not only can you connect with other patients and caregivers on healtheo360, you can also view members' stories and videos; watch the 360 Interview Series with another Alzheimer's caregiver; and join online support groups, such as the one on our website for the Alzheimer's Association, NYC Chapter.

Many prefer participating in an online caring community to traditional support groups, as this type of community is right at your fingertips when you need them without having to leave the comfort of your home or the side of your loved one. With over 250,000 visitors, the NYC Chapter support page is one of the most active on the site due to the educational videos and materials available free of charge to visitors and members.

There are many helpful videos with caregiving tips, recipes, and insight on finance management. Additionally, one can read journal entries about what it is like to be newly diagnosed, offering an inside look at how Alzheimer's patients think and feel. There are many people waiting to hear your story and support you through this time. For additional information and benefits, please visit www.healtheo360.com.



Share Your Story

Find support. Encourage others.
Learn, inspire and belong.

healtheo360 is a caring community for patients with chronic conditions, caregivers, family members and friends to share their stories of inspiration, motivation and support.



Share Your Story

Share your experience to improve your life and the lives of others who are "just like you" through video or journal stories.



Join Support Groups

Connect with advocacy organizations, participate in support group discussions, share ideas and receive information on various health topics.



Get Valuable Perks

Receive valuable services and exclusive discounts from our trusted partners - FREE for the healtheo360 community.

Join for FREE today at www.healtheo360.com



Paid Advertisement

Dementia Care Training for Professional Caregivers Graduation



Jankey Arjume, Dennis S. Bartido, Yovanne Chery, Shvanta Culler-Jones, Avril Fecker, Anna Glodek-Ulman, Rhonda Henry, Roopattie Itwaru, Daisy Jones, Olga Joseph Dautruche, Stephen Klein, Lisha Pascall, Grazyna Perko, Chadroutie Prahalad, Renae Roberts St. Hilarie, Luzviminda Sevilla.



Yvonne Bailey, Agnes Booker, Georgett Brown, Carmel Calvan, Dawn Campbell, Ann Marie Charles, Floronte Coronel, Yanson Crawford, Nora Devlin, Marian Flynn, Cecilia Henry, Natalie King-Hodge, Madeline Pai, Oneka Ross.

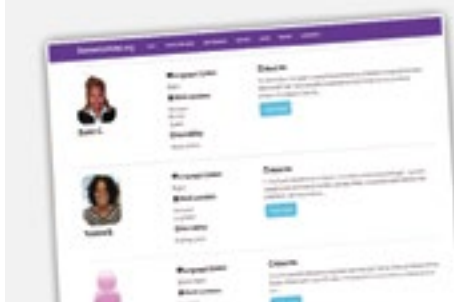


Aracelis Bravo, Lina Casado, María Lantigua, Juana Martinez, Dinorah Martinez, Lucía Payano, Rosa Reynoso, Mirian Rivera, Rosaria Rosales, Marlene Sanchez, Minerva Sierra, Francisca Taveraz, Sandra Torres.



Dolores Alava, Marta Baltazar, Aurora Chavarriaga, Isis Estevez, Dilsia Hernandez, Cristina Japa Polanco, Haydee Medina, Ana Moran, María Lourdes Nocelo, Betsy Robinson, Anamary Rodriguez, Ramona Santos, Galo Zurita.

Looking to hire private homecare workers?



DementiaAides.org can help!

Sign up, post a free ad, browse profiles.

African American Outreach Update



Paula Rice

Manager, African American Outreach
PRice@alznyc.org

During the late summer months and the early months of fall, African American Outreach embarked on a new initiative. We partnered with GrowNYC and 125th Street Farmers Market. GrowNYC is a nonprofit that sponsors 54 farmers markets throughout the boroughs and 125th Street Farmers' Market is the flagship site of Governor Cuomo's FreshConnect program. The markets attract over 250,000 customers a week and introduces fresh produce and local farmers to

communities that may not have had prior access to such. Residents are also exposed to healthy alternatives in food preparation, lifestyle choices and wellness.

The weekly visits to 125th Street Farmers' Market and Grow NYC's Brooklyn Borough Hall and Bronx Borough Hall sites yielded a robust cross section of residents eager to learn about additional services offered through the Chapter. Many had experiences with Alzheimer's caregiving while others were seeking support groups, legal advice and care consultations. We ran out of literature by the end of each day's visit, suggesting that our visits were



valued and needed in the community. Through the success of the farmers' market outreach, we learned of the community's growing needs and plan to expand our participation at more markets in 2015.

Chinese Outreach Update



Fai Lin (Fanny) Lau

Manager, Chinese Outreach
FLau@alznyc.org

Gong Hey Fat Choy and Happy Chinese New Year! From February 19 to March 5, 2015 we will celebrate the Chinese Lunar New Year, the Year of the Goat. The Chinese always say that you need to review the past in order to prepare for the future. So let us review all of the activities our Chapter has provided for Chinese clients and the community since July 2014.

On September 6, we hosted a caregiver trip to Fire Island, Long Island. Forty-five caregivers and persons with dementia participated in this outing.

On October 15, we hosted a Brain Health Day in Chinatown with numerous sponsors. Over 350 community members participated in this event to learn more about Alzheimer's disease.



On October 22, we co-hosted the Asians Physician Dinner with Visiting Nurse Services of NY and other partners. James Galvin, MD of NYU Langone Medical Center presented about depression and dementia to more than 100 physicians.

On October 29, twenty-five Chinese caregivers and persons with dementia attended the inaugural Alzheimer's Café in Chinatown. This program allowed caregivers and persons with dementia to meet and socialize with others who share similar experiences.

On December 5, we held a luncheon was held for Chinese caregivers. Dr. Clara Li gave a great presentation on Alzheimer's research. Over 40 people enjoyed a great lunch and also

learned about Alzheimer's research. They also signed advocacy forms so that their voices can be heard.

In 2015, we hope to extend the Alzheimer's Café to Queens and to hold them quarterly. Also, we hope to push the MedicAlert® + Alzheimer's Association Safe Return® program within the Chinese community. Very often, we hear about wandering or missing persons with dementia. Informing the community about this program would be greatly beneficial. Thanks to the support of Councilman Peter Koo and others, we will continue to offer scholarships to those who have difficulty paying the one-time fee for this program.

Junior Committee Update

By Marielle Mindlin Bernstein
Junior Committee President

The Junior Committee (JC) provides opportunities, comfort, and a platform for young professionals in the NYC area who have been affected by Alzheimer's. The great thing about our committee is that everyone who comes looking for a way to get involved is welcomed with open arms. In 2014, over fifty people reached out to join the JC, one of who was Christina Davis. "I joined the JC at the end of my grandmother's battle with Alzheimer's. It was so comforting to be around other young people who cared about the disease and were not dismissive of its immediate effects on our generation." Many others have shared that they joined the JC because they were tired of feeling helpless and were looking for a way to give back. Here are some of the various ways JC members contributed and channeled their emotions into action in 2014.

Advocacy: JC members attended the Rally Day in Albany to lobby for state legislation, and the Advocacy Forum in Washington D.C. to lobby for federal legislation. As JC Advocacy Chair Jessica Albin states, "It's up to us to make the change we need to see. We are never going to get the funding and attention we deserve if we don't go in person and ask for it ourselves." JC member Vanessa Vega, who attended both trips said, "Nearly every legislator I met with had been touched by Alzheimer's in some way. When they realized how little funding Alzheimer's receives, they were outraged. By bringing

this to their attention and asking for more funding, I felt like I was doing my part to prevent others from suffering the way my family had."

Outreach: For those who want to volunteer directly with the Alzheimer's community, the JC offers a monthly Outreach program at an assisted living home where we engage and interact with residents through the magic of art. Over twenty JC members volunteered through this program in 2014. As our Outreach Chair Shweta Balakrishnan explained, "By sparking creativity through art sessions and relaying stories of each other's past experiences, we are able to keep residents more cognitively aware and in higher spirits. I will never forget the smile on one resident's face as she told us 'You guys make me so happy when you visit. You make my day.' The funny thing is, she didn't realize that they do exactly the same for us."

Fundraising: In 2014, JC members and events raised over \$125,000! Members fundraised at our inaugural Ride to Remember spin event, as athletes in various Athletes To End Alzheimer's events, and of course for the Walk to End Alzheimer's. The JC's signature fundraiser is our annual Gala which raised \$60,000 this year. Liz Johnson, the 2013 and 2014 Gala chair shared that the event, "provides a wonderful opportunity to meet new people, get creative and plan a great party, but more importantly brings together over 250 young professionals, all dedicated to fighting this disease. The Gala provides

the perfect platform for young professionals to make a difference."

Support Group: We offer a monthly support group focused for young adults who are dealing with a parent with dementia. The group is led by Alexis Cibrano, a licensed social worker. In her words, "I choose to run the support group because young adult caregivers are typically not thought of as victims to the disease. The group is a great forum for this demographic to safely process the drawn out grieving of slowly losing a parent compounded with all of the exciting and challenging milestones they reach in their lives as young adults. Often times the members have lost the ability to turn to their parent in wanting to share the joy or seek advice, so the group provides one another with understanding and support along each of their caregiving journeys."

Christina summed it up perfectly when she said, "Showing that younger people care about this disease is crucial to ending Alzheimer's. We are not just advocating for our grandparents, but also for our parents, some of whom have early-onset, and others who are caregivers." We spend our time traveling to advocate, volunteering with the community and fundraising because that's what needs to be done to end this disease. We are so proud of all that we accomplished in 2014, but the Junior Committee is committed to providing just as many opportunities for our members in 2015.



Are you a young
professional
looking to get involved?

Join the Junior
Committee today!

www.alznycjc.org



Why I Will Always be an Athlete To End Alzheimer's

By Cindy Chin Levine
Athlete to End Alzheimer's

I joined team Athletes to End Alzheimer's (ATEA) for the Alzheimer's Association, New York City Chapter in June 2012. It was one of the most life-altering decisions that I have ever made, and ultimately, one of the best ones. My grandmother suffered from advanced stages of Alzheimer's, and when she passed away in March 2011, I knew I wanted to do something to help raise awareness for the disease. When I learned about the 2012 NYC Marathon team with ATEA, I knew it was the perfect opportunity to both raise awareness and run a marathon (at the time, the longest distance I had ever ran was 5 miles) in memory of my grandmother through a city that meant so much to her and my family. I thought it was also fate since the marathon was on her birthday. We used to always celebrate our November birthdays together, so I couldn't imagine a better way to celebrate than running through the boroughs.

Although I was prepared to make my marathon debut in 2012, Superstorm Sandy had other ideas, leading to the cancellation of the 2012 NYC Marathon. While I was extremely disappointed at the

time, in some ways, it was also a blessing. It brought our team closer together; it was like we were a part of this exclusive club, where our first marathon (for some) experience ended differently than we had hoped. Just days after the marathon was cancelled, a group of us had already signed up for other marathons together. Many of us eventually traveled across the country and even internationally representing the NYC Chapter in Pennsylvania, Virginia, Florida, and Italy, to name a few. But we still had unfinished business to attend to when we all signed up again to run the 2013 NYC Marathon.

When you bring together a group of people with two things in common — a connection to Alzheimer's and the desire to run a marathon — a bond is formed like no other. We spent months training, hundreds of miles sweating together, complaining, reliving memories of our loved ones, sharing and supporting each other's excitement and accomplishments. My teammates are some of my best friends and my running family. We are not just a group of individuals who want to run a marathon, but also a group that



Cindy and her grandmother

wants to take on Alzheimer's headfirst.

Before the 2013 marathon, I went to the team's pre-race pasta dinner where all of the speakers took a moment to acknowledge that for many of us, this was culmination of a two year journey to the finish line. Coach Brian's speech, who was part of the coaching team that helped turned all of us into better runners and probably better people, really struck a chord. Our teammates, near and far, in-person or virtually,



The 2014 Athletes To End Alzheimer's TCS New York City Marathonteam

first-time marathoners or veterans, go through months and in some cases, years of planning to get to this point. According to a 2012 study by Runner's World, only 0.5% of the U.S. population has run a marathon. From that small percentage, you can cut out the even smaller portion who runs for the Alzheimer's Association and the NYC Marathon. We're certainly special and some of us may be crazy, but there's no denying how dedicated we are to the cause.

Crossing the finish line and then seeing all of my family, friends, and teammates at the ATEA post-race reception and after party is the highlight of marathon day. It was such an accomplishment to finally run the NYC Marathon, but what was more touching was seeing how many people supported me through the journey. I know that feeling is shared by all of my teammates. As each runner came in, bundled in his or her heat sheet and poncho, we all shouted, cheered, hugged, and celebrated the shared accomplishment.

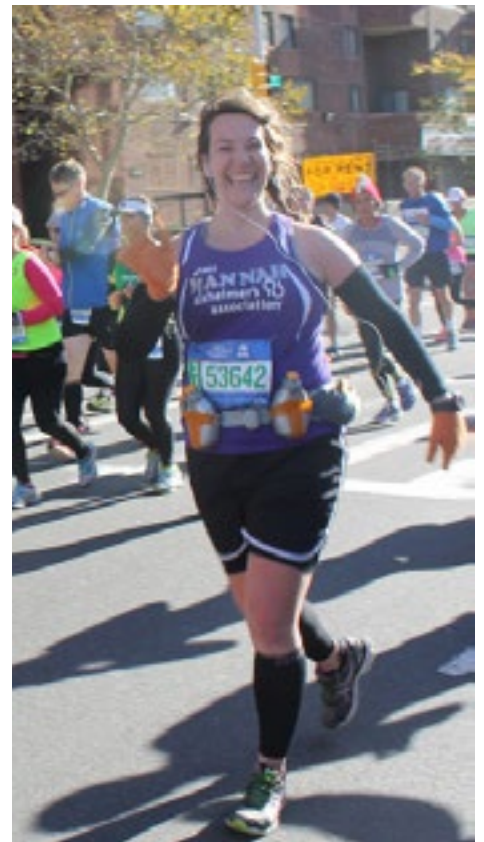
When I signed back up to run again in 2014, there was never any doubt about whether or not I would run it with Athletes To End Alzheimer's. I cannot imagine sharing that journey with anyone other than my teammates and coaches. And that will always be true regardless

of what race I run; helping raise awareness for the cause one step at a time. My grandmother's favorite color was purple, so it's fitting that I will always wear my purple Alzheimer's Association singlet proudly.

For each year I join the team, there are more and more people that I run in memory and honor of. I will continue to run in memory of my grandmother, who got me started on this crazy running addiction, but also for my teammates, my teammates' loved ones and their families because no one should ever have to watch someone they care about suffer from this horrible disease.

This year I was proud to once again cross the finish line in the company of my 133 teammates from all across the country and the world. This year, together with my teammates, we raised over \$600,000 to support the programs and services of the NYC Chapter and research towards finding a cure. I know that I speak for the team when I say that we're proud and honored to be supporting the NYC Chapter and hope to help find a cure for Alzheimer's one day.

Interested in joining Team Athletes to End Alzheimer's in 2015? Visit www.alznyc.org/athletes or contact athletes@alznyc.org.



Global Family Reunion



By A.J. Jacobs

When I started writing a book about family, I asked myself: What is the core of family life? The answer I came up with: our memories.

Alzheimer's robs us of our shared family stories. I watched my grandfather succumb to dementia and it was heartbreaking. I can only imagine the stories he never got to tell me — about his childhood on the Lower East Side, about how he opened a dry cleaning business for army officers. This realization inspired me — a writer who has never thrown a party for more than twenty people — to plan a huge event for hundreds, even thousands to benefit the Alzheimer's Association, NYC Chapter. It's on June 6th on the grounds of the 1964 World's Fair, and you're invited.

The event is a little different from your average fundraiser. As far as I know, it's the first of its kind. It's called the Global Family Reunion, and it will be the biggest, most inclusive, most star-studded family reunion in history. Everyone's invited, because the human race is, in fact, one big family. The farthest cousin you have on Earth is about a 70th cousin. Most people are much closer to you than that, even if you don't know it.

My aim is to make this a family reunion you'll actually enjoy — a

Family Reunion meets a World's Fair meets a TED conference. The day will be filled with great speakers (Henry Louis Gates Jr. of PBS's *Finding Your Roots*, NPR's Scott Simon and Dr. Oz, among many others). There will be comedy, contests, booths, games for kids, crafts, and music — Sister Sledge is coming to sing "We Are Family" live.

Scientists will present about the latest advances in Alzheimer's care and research. There will be a Memory Wall with photos of family members affected by Alzheimer's. And singer-songwriter Jonatha Brooks will perform part of her *New York Times*-praised play about Alzheimer's, *My Mother Has Four Noses*.

It will also be an introduction into the wild new world of family history because we've entered a new era. For the first time ever, we can figure out how any two people on Earth are related to each other. The Pope and Jay-Z; David Hyde Pierce and Lou-ellen Barkan.

This is because thousands of researchers are working on one shared family tree. It's not really a tree. It's a forest. It started out with thousands, then tens of thousands. At press time, the Global Family Tree has a jaw-dropping 81 million people on it. That's 81 million people related by blood or marriage on a single tree. It

has been built on the Internet using a collaborative, crowdsourced model on sites such as Geni and WikiTree. You put up your tree, and if any branch of your tree overlaps with someone else's tree, you can combine trees. And then you keep on combining. DNA testing also has helped alert us to thousands of new cousins.

It's remarkably easy to join this family tree. You just have to go to GlobalFamilyReunion.com and enter your grandparents' names. Once you get on the tree, it's addictive. It's thrilling to see how you're related to your heroes, your friends, your favorite actors. Granted, it's not always a close relation. For instance, Barack Obama is my fifth great aunt's husband's brother's wife's seventh great nephew. But still — we're family, at least in the broadest sense.

I know it's idealistic, but I'm hopeful that the realization that we're all one family will spur us to be kinder to each other. And maybe it will help us cooperate to solve the big problems, including Alzheimer's.

The Global Family Reunion is an enormous event, and I'd love all the help I can get to put it on. So please contact me at aj@ajjacobs.com or at www.GlobalFamilyReunion.com if you want to be involved, or just attend. Thank you my cousins.

Plaques and Tangles in 3-D: Relevance for Alzheimer's Disease Drug Testing

By Merina Varghese, Ph.D.
Postdoctoral Fellow, Neuroscience
Icahn School of Medicine at Mount Sinai, New

One of the challenges when studying complex brain disorders is developing an appropriate experimental model that reflects many of the features seen in the disease. For instance, the two major changes in the brain used to confirm diagnosis of Alzheimer's disease are abnormal structures formed by buildup of two proteins: clumps of amyloid-beta, called plaques, outside neurons and accumulation of tau, called tangles, inside these brain cells. Many experimental models widely used in Alzheimer's disease research have either amyloid-beta plaques or tau tangles in neuronal cells in a dish or in the brains of laboratory rodents. Research has revealed that the abnormal buildup of these two proteins are connected, so an experimental model that has both plaques and tangles would help to discover the interactions between the two and to test drugs that target one or both.

Scientists have now developed a new model that shows both plaques and tangles in human neurons grown in a dish. Lead authors Se Hoon Choi and Young Hye Kim conducted the study with colleagues in the laboratories of Doo Yeon Kim and Rudolph E. Tanzi at Massachusetts General Hospital. The collaborative study also involved scientists from Korea Basic Science Institute, University of Bonn and Hertie Foundation in Germany, Boston Children's Hospital and Harvard Stem Cell Institution, the Whitehead Institute for Biomedical Research in Cambridge, MA and University of California, San Diego. Their findings are reported in the November 13th issue of *Nature*.

Choi and colleagues inserted genes for amyloid precursor protein and another protein presenilin 1, which plays a role in converting the amyloid precursor protein into toxic amyloid-

beta, into human neural progenitor cells. The genes they inserted carried mutations seen in patients with familial Alzheimer's disease, the hereditary form of the disease. The neural progenitor cell line was created from stem cells in the brain by inserting a tumor gene that enables them to keep dividing in the culture dish. As the name indicates, these cells have the capacity to develop into brain cells, including non-dividing cells like neurons. By growing these cells in a three-dimensional gel scaffold, or 3-D matrix, under specific conditions, the scientists obtained functional mature brain cells, both neurons and glia, in three dimensions. The presence of the mutant amyloid-beta and presenilin 1 proteins led to production of toxic amyloid-beta and, by concentrating the amounts of amyloid-beta in the 3-D matrix, resulted in the formation of amyloid-beta plaques. What is more exciting, the human neurons in the 3-D cell model also produced modified toxic forms of the tau protein similar to those seen in Alzheimer's disease, resulting in tau tangles. The scientists further demonstrated the power of this new model in drug discovery. Their experiments showed that drugs that can decrease formation of toxic amyloid-beta also lowered toxic tau. However, a drug that reduced toxic tau did not change levels of toxic amyloid-beta.

The information gained from the 3-D cell model about the interactions of amyloid-beta and tau will be invaluable to understand the changes seen in Alzheimer's disease, with the caveat that the gene mutations used to create the model are present only in familial cases, where the disease is healthy. The effects of these proteins on the other brain cells, glia, that are present in the 3-D cell model and the sequence of changes connecting abnormal amyloid-beta and tau are areas yet to be explored. A major

advantage of this experimental model is that scientists can use it to test drugs targeting both plaques and tangles in a few weeks, as opposed to several months required for the plaques or tangles to form in laboratory rodent models. The drugs that can reduce amyloid-beta and/or tau in the 3-D cell model can then be tested for effectiveness and safety as well as for their effects on remedying Alzheimer's disease-like cognitive deficits in animal models. As shown by the authors in their experiments with drugs targeting amyloid-beta versus tau, the model also enables the discovery of agents that can hit both targets or that are more specific. Thus, the 3-D cell model provides the scientist with a valuable new tool for furthering drug discovery in Alzheimer's disease. Of course drugs that look effective in this system would need further testing, however, the method allows us to rapidly examine the effect of many possible molecules and take the best ones into the more expensive animal and human studies.

Reference:

Choi SH, Kim YH, Heisch M, Sliwinski C, Lee S, D'Avanzo C, Chen H, Hooli B, Asselin C, Muffat J, Klee JB, Zhang C, Wainger BJ, Peitz M, Kovacs DM, Woolf CJ, Wagner SL, Tanzi RE, Kim DY. A three-dimensional human neural cell culture model of Alzheimer's disease. *Nature*. 2014 Nov 13;515(7526):274-8. doi:10.1038/nature13800.

Sources:

Mary Sano, Ph.D., Professor of Psychiatry, Icahn School of Medicine at Mount Sinai, and Director of Research, James J. Peters Veterans Affairs Medical Center, New York; Merina Varghese, Ph.D., Postdoctoral Fellow, Neuroscience, Icahn School of Medicine at Mount Sinai, New York.

Understanding Dementia Seminar: What You Need to Know and Where to Go

Sessions provide family members and friends with information about Alzheimer's, other types of dementia and resources and services available.

Upcoming Dates in English:

February 10	5:30 – 7:30 p.m.	Manhattan
February 12	12:30 – 2:30 p.m.	Queens
February 13	Noon – 2:00 p.m.	Manhattan
February 18	1:00 – 3:00 p.m.	Brooklyn
February 18	5:30 – 7:30 p.m.	Manhattan
February 25	6:00 – 8:00 p.m.	Upper Manhattan

March 5	12:30 – 2:30 p.m.	Queens
March 10	5:30 – 7:30 p.m.	Manhattan
March 13	11:00 a.m. – 1:00 p.m.	Bronx
March 13	Noon – 2:00 p.m.	Manhattan
March 18	5:30 – 7:30 p.m.	Manhattan
March 18	6:00 – 8:00 p.m.	Brooklyn

April 2	12:30 – 2:30 p.m.	Queens
April 10	Noon – 2:00 p.m.	Manhattan
April 14	5:30 – 7:30 p.m.	Manhattan
April 15	1:00 – 3:00 p.m.	Brooklyn
April 15	5:30 – 7:30 p.m.	Manhattan

Upcoming Dates Just for Professionals:

March 11	3:00 – 5:00 p.m.	Manhattan
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Upcoming Dates in Spanish:

February 11	6:00 – 8:00 p.m.	Upper Manhattan
March 13	1:00 – 3:00 p.m.	Bronx

Medicaid Home Care Seminar: A Practical Guide to the System

Caregivers are guided through the application process for Medicaid home care service.

Prior attendance at a Legal & Financial Seminar is required.

Upcoming Dates:

February 5	5:30 – 7:00 p.m.	Manhattan
March 5	5:30 – 7:00 p.m.	Manhattan
April 2	5:30 – 7:00 p.m.	Manhattan

Please call our
24-hour Helpline at
800-272-3900
to register for meetings.

**Registration is required.
Space is limited.**

Placing Your Relative in a Nursing Home

Sessions educate caregivers about the steps involved in nursing placement, paying for care, easing the transition and being a successful advocate for the resident.

Upcoming Dates:

February 17	5:30 – 7:00 p.m.	Manhattan
March 17	5:30 – 7:00 p.m.	Manhattan
April 21	5:30 – 7:00 p.m.	Manhattan

Legal & Financial Seminar

An attorney specializing in Elder Law discusses important topics caregivers should understand before meeting with a personal attorney. Topics include Power of attorney, Guardianship, Medicaid Eligibility, Long-Term Care Insurance, Health Care Proxy and more.

It is recommended that you attend an "Understanding Dementia: What You Need to Know and Where to Go" seminar prior to attending this meeting.

Upcoming Dates in English:

February 2	Noon – 1:30 p.m.	Manhattan
February 23	5:30 – 7:00 p.m.	Manhattan
February 26	5:30 – 7:00 p.m.	Manhattan

March 2	Noon – 1:30 p.m.	Manhattan
March 16	5:30 – 7:00 p.m.	Manhattan
March 26	5:30 – 7:00 p.m.	Manhattan

April 6	Noon – 1:30 p.m.	Manhattan
April 20	5:30 – 7:00 p.m.	Manhattan
April 23	5:30 – 7:00 p.m.	Manhattan

All meetings are free of charge and subject to change.

You may notice that specific locations of upcoming meetings are not listed. You will receive location information during your registration call.

We wish to thank the following community partners:

CAPE at the Samuel Field YM-YWHA
Riverstone Senior Life Services
Heights & Hills
Presbyterian Senior Services

Monthly Education Meetings

Upcoming Dates (all meetings from 6:00 - 8:00 p.m.):

February 9

Topic: Legal Empowerment and the Health Care System: Know Your Rights

This meeting will provide the details on the essentials of Health and insurance advocacy.

Speakers: Mira B. Weiss, Esq.
Deborah F. Truhowsky, Esq.

March 9

Topic: Accessing Home Care in 2015

Major changes are happening that will affect people who need home care, who have both Medicare and Medicaid. Important information regarding these changes will be shared at this meeting!

Speakers: Peter Travitsky, LMSW, JD
New York Legal Assistance Group

April 13

Topic: Driving & Dementia

Meeting description

Speakers: TBD



RSVP online for Monday Educational Meetings at
www.alznyc.org/educationreg

The Elephant Series



These meetings address topics that tend to be particularly challenging to caregivers and cover issues that many would much rather pretend they did not need to discuss. When you see our Elephant Series logo, we hope you'll take a moment, and ask yourself honestly if this is a topic you can afford to turn away from or if this is one that is simply too big to be ignored.

Family Caregiver Workshops

During this 10-hour workshop, caregivers learn to view the world from the perspective of the person with dementia. They also learn how to communicate more effectively with the person for whom they are caring and receive new insights on how to manage the challenging behaviors often associated with Alzheimer's disease, as well as the importance of self-care.

Upcoming Series Dates:

February 5, 12, 19, 26 - Manhattan
12:00 - 2:30 p.m.

March 2, 9, 16 & 23 - Manhattan
5:30 - 8:00 p.m.

April 9, 16, 23 & 30 - Brooklyn
Noon - 2:30 p.m.

April 18 & 25 - Saturdays
10:00 a.m. - 3:00 p.m.

Attendance is required at all workshops in a series.

Upcoming Events

**FEB
12**

Mind & Body

"Mind and Body for Caregivers" incorporates gentle chair-yoga, as well as breathing and relaxation techniques for caregivers. Please call our 24-hour Helpline at 800.272.3900 to register.

**MAR
3 & 12**

**APR
7&9**

**FEB
9**

We Sing & Dance

Join us for an afternoon of singing and dancing with staff members from Rhythm Break Cares and the Alzheimer's Association, New York City Chapter! Refreshments will be served. Please call our 24-hour Helpline at 800.272.3900 to register.

**MAY
6**

Charles Evans Annual Lecture on the Art and Science of Caregiving

A Place Beyond Words:
The Literature of Alzheimer's
www.alznyc.org/caregivinglecture
These event is free of charge.

New York City Chapter

360 Lexington Avenue, 4th Floor
New York, NY 10017

CHANGE SERVICE REQUESTED

www.alz.org/nyc

646 744 2900

800 272 3900 — 24-hour Helpline

