At Deadline: The NYC Chapter was named the Agency of the Month by the New York Nonprofit Review
Dear Friends,

Dinner parties just aren’t what they used to be. A decade ago, I would get quizzical looks when the dinner host introduced me as the new President & CEO of the New York City Chapter of the Alzheimer’s Association. Inevitably, I would try to explain that Alzheimer’s was quickly becoming a national healthcare crisis, but the conversation soon turned to golf, vacations, grandkids, and other pleasantries.

In a little more than 10 years, how the tide has changed. Now at social events, I am the center of attention; not because I am anything special, but because there has been a startling and important sea change in Americans’ awareness about Alzheimer’s and dementia. Our national Alzheimer’s epidemic is now personal. People are worried that they, or a loved one, could be next. Whether it’s a family member, a colleague, a neighbor, a U.S. President, or a famous country singer, almost everyone knows someone who has this deadly disease.

As public awareness has grown, one thing has remained constant: the compassionate and quality care that the Chapter provides to more than 250,000 people in our New York City Alzheimer’s community. As we mark our 30th anniversary, I am very proud of our extraordinary growth and accomplishments.

Thirty years ago, in our nascent stages, the Chapter consisted of five or six devoted employees whose jobs were to answer phone calls and make referrals to other organizations that provided direct care and support. Today, we are a 60-person, $9 million, nationally respected nonprofit offering hundreds of free educational initiatives and support services, and a myriad of other programs, for New Yorkers with the disease and their caregivers. I’m also proud to say that the professionals who staff our 24-hour Helpline answer an astonishing 1,500 calls a month!

Not only has our Chapter undergone significant expansion — tripling our office and service space to include an innovative Early Stage Center — we have also opened satellite offices in Brooklyn and Queens, bringing our experts where the need is greatest. Responding to the growing need in the African American, Chinese, Latino, and Russian communities, our culturally sensitive specialists are there to serve the nuanced needs of these diverse populations.

Like many Chapter programs, MedicAlert® Foundation + Alzheimer’s Association Safe Return® was created to fill a real need in our community. Jed Levine designed the prototype in 1990 to respond to the serious problem of wandering among people with dementia. Little did he know that his creation would become a national program that has saved thousands of lives. Today, nearly 23,000 New Yorkers are protected by this critical resource.

Alleviating suffering and providing comfort for people with advanced dementia and Alzheimer’s is the goal of a pilot project launched by the Chapter in 2013. Called Palliative Care for Advanced Dementia and based on the “comfort-focused care approach” developed by Beatitudes Campus, it helps nursing homes better identify and manage physical pain, emotional distress, weight loss, and sleep disturbances. The program will change the way dementia-related end of life care is provided.

From our relationships with major museums in offering cultural and respite activities, to our core support group programs, we take the business of providing services very seriously. As a charity that relies heavily on donations from the public, major funders, and foundations, we have an obligation to ensure that our programs work and that they work well. With the help of a full-time PhD whose background is statistical evaluation, we now assess the viability of every program before it starts and analyze the outcome of every initiative after it ends. With empirical proof that our efforts are effective, we impress our partners and supporters.

The truth is, the more things change, the more they stay the same. So, whether you are 40 years old with early-onset or 90 and in the late stage of dementia, our dedicated Chapter professionals will be with you and your family every step of the way helping you move along the continuum. You will never be alone. Compassion, creativity, and innovation have been the hallmarks of the New York City Chapter of the Alzheimer’s Association for more than 30 years. That will never change.
As we look back on the 30 years since the Chapter was re-incorporated in 1985, we have an opportunity to reflect on the growth of the services, the increase in demand and the direction going forward as we strive to meet the needs of New Yorkers with dementia, their family caregivers and the professionals who care for them. And, as I look back on my 25 years with the Chapter, I am proud of all we have accomplished and am keenly aware of all we have yet to do.

In 1985 approximately 2 million Americans had Alzheimer’s. Now, there are over 5.3 million with Alzheimer’s and that number is growing. In 1985, there were no treatments and no clear diagnostic guidelines. Now, there are four approved treatments for the symptoms of the disease and revised, clear guidelines for diagnosis. There were no biomarkers in 1985. There are now methods of detecting amyloid in living brains. We have clearly come a long way in our understanding of the disease and treatments of symptoms, but still await a drug that truly modifies the disease and a definitive way of preventing, slowing down, or stopping the disease.

In the absence of an effective treatment, prevention, or way of slowing down the disease, we have learned so much about improving the quality of life for persons with the disease as well as for those who care for them. Interestingly, the roots of those approaches were apparent even in the 1980’s and early 1990’s when I joined the Chapter: respect for the individual with dementia, a deep understanding of the caregiver’s emotional journey, and the knowledge that with support, families can survive the challenges of caregiving — and that you cannot do it alone.

The Chapter was a small but effective organization when I joined as a staff member in 1990. Nine staff members were assisted by a host of volunteers who, among other tasks, answered the 24-hour Helpline from their homes on nights, weekends, and holidays. We built our extensive support group network, and developed the training program that is now the foundation for our Dementia Care Training for Professional Caregivers (DCTPC). Care Consultation as well as the Legal and Financial Planning, Medicare Home Care, and Placing Your Relative in a Nursing Home seminars did not yet exist. The Family Caregiver Workshops were developed in the 1990’s, but were offered only two or three times a year. We brought our education meetings to the boroughs we served: Manhattan, Brooklyn, Queens, and the Bronx (Staten Island had a separate Chapter at the time).

The MedicAlert® Foundation + Alzheimer’s Association Safe Return® program launched in November of 1990 as the Helmsley Alzheimer’s Alert program, with funding from Leona and Harry Helmsley. A press conference with Mrs. Helmsley at the Empire State Building led to an invitation to meet with Senator Mark Hatfield of Oregon to discuss taking the program nationwide. Several months later, funding was allocated through the Department of Justice to expand the “wanderer’s” program across the country, and we created a structure with our National organization to manage the program.

In 1985, we didn’t have Latino, African American, Chinese, Russian, Orthodox Jewish or LGBT outreach programs. Those programs were developed in the 1990’s and 2000’s, bringing our message of hope and help to all New Yorkers in need.

We now have close to 60 staff members, but one thing has stayed constant: our commitment to excellent care and support for those we serve. My predecessor and mentor, Jean Marks, always looked at any project or opportunity and asked the question, “How does this improve the lives of persons with dementia?” She insisted on not just good care, but superb care, setting the standard of excellence that we maintain today. She knew then, as we know today, that there needs to be a strong voice at the table to ensure that individuals living with Alzheimer’s and their families are represented.

Our Advancing Dementia Capable Palliative Care program has its roots in our first foray into hospice care, which worked with local providers to educate them on the special needs of persons with dementia and the unique situation of their family caregivers. Our newest project brings a model of care that ensures comfort and dignity to persons with dementia throughout the course of the disease.

In 1983, President Reagan designated November as National Alzheimer’s Awareness Month. His mother had the disease, and as so often happens, because of that personal connection, he was deeply committed to increasing awareness. Ironically and sadly, 11 years later
in 1994 he wrote his poignant letter to the nation, announcing his own diagnosis and his decision to go public to help promote awareness. Twenty-one years later in 2012, the National Alzheimer's Project Act (NAPA) was signed into law by President Obama with the ambitious goal of finding an effective treatment by 2025.

We have made great strides in the area of policy and advocacy. Some of our early champions in the State Legislature, such as Assemblywoman Helene Weinstein, remain strong champions of our cause. Governor Andrew Cuomo's recent budget allocation of $25 million for care and support in New York State is an outstanding acknowledgment of Alzheimer's as a major public health concern. And since 2006, we have received funding from members of the New York City council for enrollment in the MedicAlert + Safe Return Program.

However, many things have remained unchanged:

1. Many people still struggle alone, not knowing how to access help, guidance, and support.

2. The vast majority of primary care physicians are unfamiliar with how to discuss dementia with patients and their families, and are unaware of the supports and community resources available.

3. Ethical and healthcare questions remain, such as:
   - How much autonomy to provide, and how to provide protection while maintaining self-worth and dignity.
   - When to stop using the available medications for Alzheimer’s.
   - How to set standards for training for dementia care.
   - Who will provide care for all who need it and who will pay for care?

4. Recognizing that Alzheimer’s is a terminal illness, how are we going to provide care so that everyone, even those in the advanced stages of the disease, will have the best possible experience, free of pain and discomfort, enjoying the things that give pleasure and connectedness?

Of course we have accomplished a lot, and we couldn’t do it without the support of our committed Board of Directors, the outstanding staff who carry out the work every day, and our generous and loyal donors who make it possible.

Thank you for trusting me with the responsibility of directing the Chapter’s programs for the past 25 years. I look forward to continued growth as we reach out to more communities and bring our message of help and hope to all New Yorkers.
Chapter in the News

For 30 years, the New York City Chapter of the Alzheimer’s Association has been committed to providing individuals, their families, and caregivers with the support and education they need to navigate this insidious disease. Creating public dialogue about Alzheimer’s is an important part of what we do. Through TV, radio, newspapers and the internet, we reach millions of people every year, helping them to understand what Alzheimer’s is as well as its impact on them and the world.

The newly relaunched New York Nonprofit Review featured the Chapter as its Agency of the Month for June. Read by leaders in government, philanthropy, and business worlds, the in-depth story will certainly elevate the Chapter’s profile among these important constituents.

Julianne Moore was just one of many celebrities who took part in this year’s “Forget-Me-Not” Gala, An Evening to End Alzheimer’s that included a red carpet buzzing with stars of the screen, stage, football field, and Alzheimer’s research community. Photos of celebrities, Chapter staff, and members of the Alzheimer’s community were included in Bill Cunningham’s Evening Hours column in The New York Times. Several outlets ran coverage of this spectacular fundraising event including Crain’s New York Business, the DailyMail.com, Broadway World, New York Social Diary and New York Post’s Page Six.

It was also quite the year for the Blondes vs. Brunettes® (BvBTM) fifth annual powder puff charity football game. Not only did the event raise a record-breaking $200,000 this spring, but the Blondes finally took the win! NY1 News captured the “rivalry” between the two teams in a live interview with reporter Roger Clark, who met teams on the field in advance of the game. NY1 also ran a longer piece with interviews of the players and Chapter staff.

Lou-Ellen Barkan was included in a New York Academy of Sciences podcast series, “Dementia Decoded,” along with other highly regarded professionals in the Alzheimer’s and dementia community. Lou-Ellen was featured on three segments this spring discussing a range of dementia-related issues. She has also continued writing her blog on The Huffington Post with her most recent entry titled, “Fighting Alzheimer’s: A Radical Idea,” capturing hundreds of likes, shares, and retweets. You may have also seen Lou-Ellen with caregiver Alba Sánchez on WPIX-TV’s News Closeup where they discussed at length caregiving, recent Alzheimer’s studies, and the latest Alzheimer’s Association 2015 Facts and Figures report.

Jed Levine was an important background source for the Associated Press on a story about state budget funding for Alzheimer’s. Jed could also be seen on Al Jazeera (America and English) where he discussed the issue of Alzheimer’s and wandering in a segment that included an interview with 2014 Walk to End Alzheimer’s® honoree Kenneth Shinozuka, who discussed the technology he crafted to help combat the problem of wandering. WPIX 11 also reported on a missing person that the Chapter was trying to help locate on its website.

Joining Broadway star Andy Kelso (Kinky Boots) and his wife Sheila Coyle of The Manhattan Dolls on an interview panel for Manhattan Neighborhood Network’s “Spotlight On,” Lou-Ellen addressed a number of important issues related to Alzheimer’s disease. An article and a sneak peak of the interview can be seen on The Huffington Post.

Matt Kudish, Senior Vice President of Caregiver Services, and Lauren Volkmer, former Dementia Care Trainer and now Manager of Early Stage Services at the Chapter, were interviewed on Staten Island Community TV. The piece, which included a discussion about caregiving, ran several times throughout the month of March. New York Nonprofit Press (now New York Nonprofit Daily) and Senior Housing News both included the appointment of Cheshire Schanker as a Chapter Care Consultant in recent issues.

Broadway World also ran two stories about the Chapter’s Theater Benefit, It Shoulda Been You, directed by Chapter friend, Alzheimer’s advocate, and Tony® Award-winning actor David Hyde Pierce. Media also included this event as well as the Gala in their print and online calendar of events.

Stay tuned for more Chapter in the News!
Dear Helpline

I’m caring for my mother who was diagnosed with dementia five years ago. She’s getting much worse, and I am getting more frustrated. I’m managing her finances and daily activities as well as my own. I have three siblings, one who calls occasionally, none of whom are helping me. I feel alone in this battle. What can I do to help my mom and encourage my siblings to be more involved?

- Stacey

Stephanie Aragon
Manager, Helpline
Helpline@alznyc.org

One of the difficulties that family caregivers often face is feeling alone in the caregiving process. Feeling lonesome and overwhelmed can contribute to anger and depression. How does anyone manage the big issues as well as the many more minute aspects of getting a family member through her day?

You need help with establishing a routine for your mother that includes your siblings’ participation. Here at the Chapter, we offer individual and family counseling with licensed social workers through our Care Consultation program. You can make an appointment for a one-on-one meeting, in person or over the phone. Your Care Consultant will discuss the challenges you are facing and can even hold a meeting with you and your siblings in person, or on a conference call, to discuss the current situation in detail and assist in developing a care plan for your mother.

Your Care Consultant may explore different types of respite options for your mother’s care and provide information about adult day centers. These are programs that provide opportunities for socialization, activities, and programming specific to people with dementia. As participants arrive at the center, they engage in activities, which may include chair yoga, painting, making collages, or listening to music and singing. Many centers also serve a hot, nutritious lunch. Some centers even provide transportation.

Care Consultants can give information about home care as well, including a list of options. Home care is a service that allows people with dementia to obtain healthcare in their own home. A home care worker may come a few hours a day for a few days a week, or every day for many more hours. The Chapter offers a nationally recognized training program to train home care workers in dementia care; those aides are listed on TogethersWeCare.com, our web-based resource for families seeking to hire private aides trained by the Chapter. Home care workers help with activities and socialization as well as with bathing, dressing, feeding, toileting, meal preparation and more.

A larger issue may be paying for the respite option that is best for your situation. Our Care Consultants can discuss financial options with you and your family. You may be encouraged to attend our Legal and Financial Seminar as well as our Medicaid Home Care Seminar to get acquainted with the legal and financial issues associated with planning and paying for long-term care for a person with dementia.

It’s also essential that you remember to include self-care in your calendar. Schedule time for yourself. Go to the movies, exercise, spend time with friends. Read a book, take a nap, have your hair or nails done. Anything you can do to recharge your battery so that you can continue to provide the highest quality care to your mother is going to be helpful and reinvigorating.

Support groups are another lifeline for family caregivers. The Chapter currently offers over 110 support groups across NYC, some specifically for adult children caring for a parent. Many of our group leaders, who have been professionally trained by the Chapter, have been through the caregiving experience, so they “get it.” Group members have the opportunity to share not only dealing with practical matters, but also navigating family issues and coping with the myriad of feelings that arise when caregiving.

If your siblings can’t take time to visit with your mother, they may be able to help in other ways such as paying bills, arranging doctors’ appointments, calling her on a regular basis, and making sure you have time for yourself. They can send for and read the many books that have been written on the subject of dementia and share information. They can accompany your mother to doctor or dentist appointments. They can also plan a small birthday party or Mother’s Day event at your mother’s home or elsewhere, order the food and celebrate the occasion.

You should not feel alone in caring for your mother. By arranging a Care Consultation with your siblings, joining a support group and attending our seminars, you can receive the information, comfort and support you need.

Connect with our Care Consultation program by calling our 24-hour Helpline at 800-272-3900 and asking to speak with a Care Consultant.

www.alz.org/nyc

www.alz.org/nyc
Support Groups

Evolution of the Support Group Program

The Alzheimer’s Association, NYC Chapter’s support group program was established in the mid-to-late 1980’s. At that time, it was clear that family caregivers needed to share their experiences, feelings, and frustrations about an often misdiagnosed and misunderstood disease. Then, as they do now, support groups offered a respite from the isolation and loneliness that often accompany caregiving.

Support groups originally focused on sharing information and resources with caregivers and discussing practical issues that arise during day-to-day care for persons with dementia. Under the leadership of Rea Kahn, RN, a psychiatric nurse and a psychodynamically trained group leader, the Chapter began to form and offer family caregiver support groups, which focused on both the emotional impact of the disease and the practical challenges of caregiving. This change in emphasis enabled caregivers to express all of their feelings related to caregiving including despair, anger, and resentment — feelings often impossible to express to friends or other family members.

Rea developed groups throughout the metropolitan area and, at the same time, trained volunteers and professionals without prior experience to become support group leaders. Eventually, she developed a formal support group leader training program that has evolved into the present day Support Group Leader Training Workshop conducted at the Chapter by Sharon B. Shaw, LCSW, CGP.

Sharon has been involved with the Chapter since 1985. In 1991, she formed and co-led a support group for spouses that she continues to lead to this day. Sharon worked with Rea until her retirement in 2000. As Rea’s retirement was nearing, she approached Sharon to take over the role of Support Group Leader Trainer.

Since 2000, Sharon has trained over 450 support group leaders. The training prepares volunteers and professionals to lead groups both at the Chapter and in community settings, as well as to educate and advocate for caregivers within their communities and organizations. Sharon also developed and continues to lead monthly supervision groups, which provide an opportunity for group leaders to continue their learning and to process the material that emerges in their groups.

I joined the Chapter as its Support Group Manager in 2003 when my predecessor Sheila Crandles departed for the West Coast. I have expanded the educational aspects of the support group program, and organize and lead quarterly educational workshops for support group leaders on helping their group members address difficult topics such as the need to mourn, palliative care, and the end of life. Under my leadership, the Chapter now also offers bereavement groups for group members.

The support group program believes support, education, and training are essential for group leaders whose work involves the difficult task of helping people to survive a long, degenerative, and incurable disease. Without ongoing support and education, group leaders risk suffering burnout, emotional distress, and even physical illness.

Sharon and I am committed to creating an atmosphere in which group leaders can grow as both leaders and as professionals in their chosen fields. Given the long-term commitment of many of our groups leaders (some have been leading groups for over 20 years), it is clear that the Chapter’s approach to recruitment, training, supervision, and education has been effective in sustaining a strong network of groups and group leaders.

To learn more about the Chapter’s support groups, or if you are interested in joining a group, please visit www.alz.org/supportgroups or call our 24-hour Helpline at 800-272-3900.

After more than 12 years managing the NYC Chapter’s support group program, Wendy Panken retired in late July.

Wendy assisted countless caregivers in their search for support groups, and developed a robust network of volunteer support group leaders throughout New York City.

Her expertise and dedication will be missed. We wish her all the best in her future endeavors.
Early Stage Services

Mind & Body: a Chance to Connect

The New York City Chapter of the Alzheimer’s Association is incredibly proud of our Harry and Jeanette Weinberg Early Stage Center. The Center offers many different types of groups for people with early-stage memory disorders. In February 2014, we began to offer Mind & Body, a weekly yoga and relaxation group. This program allows participants to take time to care for themselves and focus on their overall well-being. For one hour, we are able to drop any worries or to-do lists, and spend time together just to breathe and feel.

Living with an early-stage memory disorder has very unique challenges and stresses, and it is very important to take time out to relax. During our sessions, group participants utilize many breathing, meditation, and movement techniques to calm their nervous systems and de-stress, as well as to lengthen and strengthen their bodies. The exercises we do often focus on symptoms or issues that are common to the group and to seniors in general. For instance, we do many exercises to improve balance and coordination, in an effort to reduce the risk of falling. We also try to focus on digestive health, which many people struggle with due to side effects of their medications. Reducing stress can affect a person’s mood and improve his or her overall health and well-being; this can be very helpful in managing other dementia symptoms.

The main goal of our sessions is to feel better when we leave than we did when we came in. This means that we especially focus on doing what feels good in our bodies today. For each participant, each pose will feel and look different, too. We usually begin the session with a few moments of seated meditation, checking in with how our bodies feel. We then begin to bring our awareness to our breath; for the full hour, we concentrate on our breathing. Focusing on the breath means that we are paying attention to what is happening in the moment, and not to anything else going on in our lives. Slowing down our breathing actually calms our nervous system and is a great way to reduce stress. This attention to the breath has the added benefit of keeping us safe; if we go into a pose too far and lose our deep breathing, it alerts us to take a step back.

We then start to link our breath and movement together in a very mindful way. Some of our favorite sequences and poses include sun salutations, the eight movements of the spine, self-acupressure massage, tree pose, and victory pose. All of our poses are done seated in a chair or standing, eliminating the need to get down on the floor. There are many versions of each pose, which means each person can participate in a way that feels comfortable for him or her. Sometimes we will try three versions of sun salutations in one session.

Often at the beginning or end of group, we will read a passage from a book or magazine, a poem, or some other written word that inspires us.

As one Mind & Body participant shared “No matter what is going on in my week, I know I have this group. It’s the highlight of my week!” Mind & Body is a very special time for all of us who come together for a chance to connect to our bodies, our breath, and, most importantly, each other.

The Chapter also offers a version of Mind & Body for caregivers of people with dementia. Sessions are offered during both day and evening hours.

To learn more about the New York City Chapter’s Early Stage Services, including the Harry and Jeanette Weinberg Early Stage Center, as well as the Chapter’s Caregiver Mind & Body group, please call our 24-hour Helpline at 800-272-3900.

The Chapter is grateful to all of the generous donors of our Early Stage Services, in particular, Jeffrey N. Jones and The Warner Foundation, Inc.
Caring for a family member with Alzheimer's disease or dementia can be all-consuming. Caregivers often postpone their own planning needs while dedicating themselves to caregiving, often with disastrous results for both the family and the caregiver. As an elder law attorney with over 20 years of experience, I have witnessed the impact on families who lack the following legal tools: the power of attorney, the healthcare proxy, the living will, an estate plan such as a last will or trust, and the newest document, the Digital Diary, which lists passwords and access to online and computer assets. For families affected by Alzheimer's and dementia, legal planning is crucial.

To address this problem, my colleague Joanne Seminara and I wrote a practical guide on five essential legal and estate planning tools called 5@55: Legal Tools for Mid-Life Planning. Our hope is to establish age 55 as the ideal age to get your legal house in order, as life and health can begin to change at this age.

Around age 55, your role in your family and your work is seen in a new light. The passage of time becomes an important factor and you feel the need to make decisions and choices. Your children leave the nest with new generations emerging, and at the same time, your parents age. You may see your partners, spouses, and significant family members begin to need your help and care. Your own health also changes and may decline. You start to face retirement. You procrastinate and say “Tomorrow I will make a plan for my later life.” Or maybe you say “I will plan ahead when I need it,” or “When I can save some money...” The excuses are plentiful, but age 55 is the ideal age to take stock in your lives.

Why is 55 the crucial age?
Age 55 has been determined to be the optimum time to begin estate planning. Most individual child-rearing responsibilities are coming to an end and the focus can now turn to taking initial precautionary steps to prepare for the major health changes that often begin in the mid-50s. The 5@55 campaign sets age 55 as the deadline, giving direction and momentum to make this necessary step.

Why do people procrastinate and fail to plan?
You have been educated to carry insurance to cover a wide variety of emergencies, so as to protect dependents. You are routinely programmed to buy health, fire, and auto insurance without giving the purchase a second thought. These safety nets, whether legally required or not, are accepted forms of protection. Yet people, especially busy caregivers, tend to skip the equivalent legal safety net of completing the five essential legal documents identified by the 5@55 campaign. These 5@55 tools ensure that your life choices and health decisions will appropriately avoid family crises and prevent future legal problems.

Bringing the problem to light
Health emergencies can sensititize you to the need to plan; famous cases make the headlines, such as the Florida right-to-die case involving Terri Schiavo, that went all the way to the Supreme Court for a deciding opinion. Many impulsively say “just pull the plug,” but it is not so simple. When it comes to money, you often hold financial data close to your vest and want to keep your finances a secret. Financial issues stay behind closed doors. Family members may have no clue about your income and assets. The 5@55 campaign hopes to bring these issues out of the closet. The book and campaign feature relatable stories that demonstrate why legal planning is essential, especially when caring for an individual with Alzheimer’s.

How do you join the 5@55 campaign and get your legal house in order?
Call a practicing elder law to draft and execute the five needed documents. Request a Digital Diary from the 5@55 book with other forms for your review. The 5@55 method offers you that peace of mind and a path to make your planning process successful.

To receive your sample Digital Diary, contact Judith D. Grimaldi at jgrimaldi@gylawny.com or Joanne Seminara at jseminara@gylawny.com.
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In June, New York Nonprofit Review named the NYC Chapter Agency of the Month.

By Rosalyn Retkwa

Keith Amparado first noticed major changes in his mother’s personality when the two of them were planning his father’s funeral. He says her forceful responses to minor disagreements were out of character for his “extremely dignified” mother, who had once been an actress with the American Negro Theater and had gone on to a long career with Consumers Union.

At one point in their discussions with the funeral director, when Amparado interjected with something he wanted, she said: “Well, you can just pay for the entire funeral yourself.” But when he gave the funeral director his credit card, she grabbed it back and said: “This is my husband, and I will take care of the arrangements.”

She would start an argument, but then “in another minute, the whole thing would be gone,” Amparado says, which he describes as one of the “hallmarks” of Alzheimer’s — a progressive, still-mysterious disease of the brain that affects memory, thinking and behavior. “Most people will initiate an argument, and at best it trails off, but it just doesn’t stop and go away,” Amparado says.

An assistant director in New York University’s information technology division, Amparado says his faculty staff-assistance program referred him to the Alzheimer’s Association, and he took every available course and workshop and participated in support groups. “If they had it, I took it,” he says. Amparado was his mother’s caregiver for 15 years until she died in 2011. Now he is a caregiver support group leader at the association and he also runs a support group he started at NYU.

“Memory loss is what people are the most familiar with, but it’s not just about memory,” says Lou-Ellen Barkan, the president and CEO of the New York City chapter of the Alzheimer’s Association, which is celebrating its 30th anniversary this year. When her father started calling every woman “honey,” and the men “buddy,” it wasn’t immediately obvious that he had lost the ability to recall names, she says. But then she says, “he also did something very scary.” He started writing checks to fraudulent charities, “which is very common,” she says, because people with Alzheimer’s also lose their ability to reason and their judgment is flawed.

DonnaMarie Arrigo of Brooklyn says she knew something was wrong when her mother started repeating herself: “Is it raining? I think it’s raining out.” The first group she attended was on understanding dementia and its different stages — the commonalities and the differences — and “quite frankly, it scared the hell out of me,” she says. Alzheimer’s is “very hard to accept, but you learn to accept it,” she says.

Alzheimer’s started to develop more of a public profile in 1994 when former President Ronald Reagan went public with his diagnosis. A few prescription drugs have been developed that can sometimes help people level out for a period of time, but there is still no cure. It is primarily a disease that strikes people over the age of 65, but the Alzheimer’s Association estimates that up to 5 percent of the more than 5 million Americans with Alzheimer’s have the early-onset version of the disease, which affects people in their 40s and 50s.

On its website, the association runs a service called TrialMatch™, which lets the caregivers for Alzheimer’s patients search a database that includes 225 clinical studies at nearly 700 sites.
around the country. With the baby boomers reaching the age bracket for Alzheimer’s, Barkan says, “the good news” is that the race is on to find a cure. But given the difficulty of working with elderly people with dementia, research is also “expensive and hard,” she says. “In the 11 years I’ve been here, I’ve seen 20 drugs go down the tubes,” she says, though there are now “three drugs of interest.”

In the absence of a cure, most of the chapter’s efforts are focused on providing support and services to the people who care for the estimated quarter-million people with Alzheimer’s in New York City. Barkan says that when she took the helm, the organization’s budget was under $2 million; it is now $9 million this year, while its staff has grown to 60 people.

“Our support services start with our 24-hour help line,” Barkan says, noting that help is available in 180 languages through a translation service. That line is currently staffed by 12 social workers and three other people, and Barkan says she expects to add four to six more social workers because of growing demand. The line gets about 12,000 calls a year, but the volume of calls is growing by about 10 percent a month, she says.

One of the things that Barkan says surprised her was that when she started there was “almost nothing” in the way of support for early-stage Alzheimer’s patients who were “cognitively damaged in some way, but still high functioning.” So she created programs where people in that stage of the disease “could talk to a group of people like themselves.”

Barkan says the organization’s support groups are led by volunteers who are “trained and supervised by us.” Since caregivers often can’t leave their relatives alone for very long, the chapter, which is based in Manhattan, is increasing its network of in-borough support groups in Queens, Brooklyn and Staten Island, as well as its “culturally sensitive” outreach programs for the Latino, African-American, Chinese, Russian, LGBT and Orthodox Jewish communities. “Each one of the subsets has very specific feelings about Alzheimer’s,” Barkan says.

The chapter can also help caregivers find home health care aids who have completed the association’s training in caring for people with dementia. And since wandering is a big problem with Alzheimer’s patients, the chapter has about 22,000 people registered with MedicAlert bracelets in New York City. She wants to expand that program since the odds of finding someone within 24 to 48 hours is “almost 100 percent” if they have the bracelet, she says. Barkan says the chapter also trains police officers on safe return of people with dementia at the precinct level.

Of course, lobbying for greater funding for Alzheimer’s research is a big part of the effort. Currently, the National Institutes of Health provides $585 million a year for Alzheimer’s research — far less than for cancer, HIV, cardiovascular disease or diabetes — and Barkan says her organization is trying to get that increased to $2 billion. If a cure is not found before 2050, the cost to Medicare and Medicaid of taking care of a growing population of seniors with Alzheimer’s is projected to rise from $214 billion to $1.2 trillion, Barkan says — enough “to destroy the health care system.”

“This is the most costly disease in the U.S.,” Barkan says, especially since Alzheimer’s patients can live as long as 20 years after the diagnosis — though “over time, the body just shuts down,” she points out. That makes Alzheimer’s the only cause of death in the top 10 that can’t be prevented or cured, she said.

2015
Forget-Me-Not Gala

Board Member and Gala Chair, Linda LaGorga, and MC Jonathan Groff

David Hyde Pierce, Young Leadership Honoree Sam Henes and Victor Garber

Board Member Jeff Jones and Executive VP, Director of Programs & Services Jed Levine

Caregiver Leadership Honoree Kim Campbell and daughter Ashley

Creative Leadership Honoree Julianne Moore and Jonathan Groff

New York Giant Mark Herzlich with Young Leadership Honoree Sam Henes

Dinner Chair Linda LaGorga, Honoree Sam Henes with special guests Pilar and Prince Amukamara and New York Giant players

Young Leadership Honoree Mike Schnitzer, President & CEO Lou-Ellen Barkan and Young Leadership Honoree Marielle Mindlin Bernstein
Board Co-Chair Stephen Casper

Sheila Coyle and Andy Kelso

Board Member Jon Henes with wife Pam and their children Charlotte, Eleanor, Sam and CeCe.

Dorene Scolnic and Jeff Halis

Pearl and Board Member Nathan Halegua

John Fiore and Board Member Marianne Dziuba-Fiore

Michelle Lavelle, Lou-Ellen Barkan and Board Member Jim Lavelle

Board Co-Chair Ben Jenkins, Lauren Lathan and Board Co-Chair John Latham

Drs. Ralph Nixon, Steven Ferris, Mary Sano, Jed Levine, Lou-Ellen Barkan and Dr. Peter Davies

Board Member Bill Brachfeld and grandson James

Board Members Sharon Kühner, Elaine Thomas, Ben Jenkins and Lou-Ellen Barkan

Silent Auction Committee Members Debbie Prince, Shari Perlman, Maryann Falls and Chair Jamie Press
Family Caregiver Workshops, Dementia Care Training for Professional Caregivers, Early Stage Services, and outreach to diverse communities. These are just a few of the programs that did not exist 30 years ago. In the early days, caregivers attended support groups, which provided a comforting and safe environment in which to speak candidly with other caregivers facing a similar situation.

Each of these programs and many others were developed in response to need. What strengthens the NYC Chapter’s expertise in dementia care is our ability to quickly identify and respond to emerging needs, as well as our ability to develop innovative programs, which can help others locally and across the country. We are exceedingly proud of one such program that is transforming the way that care is provided in residential care facilities to persons with late stage dementia. Our Palliative Care for Persons with Advanced Dementia: Training and Implementation completed the 30-month pilot on December 31, 2014. Our goal now is to ensure that persons with dementia, regardless of the setting, have access to palliative care.

On April 22, more than 20 lead funders of this project attended our Palliative Care Funders Breakfast to hear a summary of the project, results of the rigorous five-part evaluation, and an overview of the next steps in our palliative care work. In addition to our key staff involved, each of the three nursing homes in the pilot was represented, ranging from the CEO to the staff directly involved in the program. Representatives from the nursing homes spoke movingly about the importance of this project to ensuring quality care. As one of the largest programs — in size, scope, and budget — that the NYC Chapter has ever embarked upon, it also required Chapter staff to work collaboratively to ensure a seamless operation. Below are photographs of the Palliative Care Funders Breakfast and the NYC Chapter staff that worked to make this project possible.

Thank you to all.

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 or 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@alznyc.org if you would like additional information.
How does one cope with shifting from the role of spouse, daughter, or son to that of caregiver? This question has underpinned the Charles Evans Lecture on the Art and Science of Caregiving Series since its inception. The third annual lecture, A Place Beyond Words: The Literature of Alzheimer’s, hosted by the Alzheimer’s Association, NYC Chapter on May 6 at the Times Center, took a distinct approach to this issue by examining caregiving through the written word.

Stephen Casper, Co-Chair of the Board of Directors, commenced the evening with a brief introduction that highlighted the Chapter’s double-digit growth over the past ten years. Next, Chapter President & CEO Lou-Ellen Barkan reminisced about her early days at the Chapter. In particular, she described how on her desk, along with the standard finance and personnel reports, lays an ever-growing stack of essays, novels, and screenplays by writers compelled by the challenges of Alzheimer’s. Following Lou-Ellen, Charles Evans Foundation Trustees Alice Shure and Bonnie Pfeifer Evans stressed the importance of supporting caregivers until science can deliver a remedy.

The panel consisted of two of today’s most acclaimed young authors. Stefan Merrill Block’s first novel, *The Story of Forgetting*, was an international bestseller and his work has appeared in *The New York Times* and *The New Yorker*. Matthew Thomas’ novel *We Are Not Ourselves* is a *New York Times* bestseller and was ranked on best-of lists in *The New York Times*, *The Washington Post*, and *Esquire*. Carol Levine, the event’s moderator, directs the United Hospital Fund’s Families and Health Care Project. She is deeply familiar with literature’s relationship to caregiving, having edited *Living in the Land of Limbo: Fiction and Poetry about Caregiving*.

Carol teased out the relationship between illness, caregiving, and literature by describing how 17 years as her husband’s caregiver led her to realize fiction’s power to “capture the emotional truths of caregiving,” the things we might not want to reveal to others or admit to ourselves. Stefan picked up this thread by describing the emotions he felt as a child dealing with an older family member who was neurologically regressing. He went on to discuss how reading and writing can be a connective experience for caregivers, saying that “conjuring another imagined person’s mind... can be useful in understanding where our loved ones go when they go to that place beyond words.”

Matthew continued by addressing a novel’s ability to “access an entire mind’s perspective.” In his novel he paints a picture of the early stages of Alzheimer’s as seen through a caregiver’s eyes. In doing so, he reproduces the “wall separating the consciousness of the sufferer from everyone else,” showing the inherent inscrutability in the relationship between caregiver and sufferer.

In her introduction, Lou-Ellen described how literature and film continue to promote discussions around Alzheimer’s. Concluding on a similar note, Chapter Executive Vice President, Director of Programs & Services Jed Levine drew on the spirit of community to encourage the audience to reach out to their elected officials and remind them that Alzheimer’s must be a national priority.

James Campbell is a freelance writer based in New York City. He holds an MA in International Affairs from The New School and has written for various academic and human rights organizations.
To whom much is given, much is expected.” This was the message that Kenneth A. Smaltz Sr. delivered to his son, Kenneth Smaltz Jr. It is a message that has resonated deeply with the successful entrepreneur and philanthropist who is helping to transform the lives of those less fortunate through thoughtful and strategic charitable giving.

Kenneth Smaltz Jr. is the President and CEO of K. Smaltz Inc., a company that buys and sells rare coins and precious metals, as well as the benefactor of Le Parc Place, a children’s daycare center in Maplewood, New Jersey. Investing in early childhood education is one of the ways Mr. Smaltz has been able to honor his late mother, Barbara Joan Smaltz, who was a teacher for over 20 years. In 2012, inspired by the words and actions of his father, Mr. Smaltz founded the Kenneth A. Smaltz Sr. Foundation. Since its creation, the foundation has awarded thousands of dollars in grants to organizations that provide care and support for individuals who have been affected by Alzheimer’s disease and related dementias.

Mr. Smaltz is intimately familiar with the devastating toll that dementia can have on families. In the late 1990’s Mr. Smaltz’s father began to exhibit changes in his memory and behavior. His family first became concerned when they noticed he was becoming increasingly unkempt — unusual conduct for a former marine who had once been fastidious about his appearance and keeping his home in order. In 2000 he was diagnosed with Alzheimer’s disease.

After his condition began to decline, Mr. Smaltz made the decision to have his father live with him at his home on Long Island where he served as his primary caregiver for over eight years. Anyone who has been a caregiver for a person with dementia can attest to the psychological and physical demands of this role. Mr. Smaltz, who eventually began to work from home to provide around the clock care for his father, described the challenges of this journey: “We battled all the time. It was tough, the questions he would ask me over and over again, getting up in the middle of the night to shower, believing he needed to get ready for work.” Despite the challenges he encountered, for Mr. Smaltz, there was never a question of whether or not he would care for his father. He had watched the same man who was succumbing to a fatal brain disease care for his mother every day for two years when she was ill. Whether reading, singing, or just being by her side, he was constantly present for his wife. “I’ll always remember his attentiveness to my mother. I took care of him because he deserved the same,” he said. Mr. Smaltz Sr. passed away in 2013.

In the years prior to his father’s diagnosis, Mr. Smaltz began considering the larger questions about his ultimate impact — what kind of legacy did he want to leave? What was he building? How could he be of service to others? “I started to look for people to help,” Mr. Smaltz said. Over time he became more active in his church and local community, contributing scholarship money to disadvantaged youth and hosting private fundraising events at his home. Eventually he established his foundation as a way to provide direct grants that would have an immediate impact on the lives of individuals.

“As a donor I want to see exactly where my money is going,” Mr. Smaltz declared. “I want to see people being helped.” Guided by this giving philosophy, the Kenneth A. Smaltz, Sr. Foundation awarded the Chapter a $4,500 grant to support our Special Assistance Fund, a program that offers financial support to caregivers. The fund works by providing modest, short-term, one time grants to help cover costs related to the most basic needs, including food, rent, emergency care, respite, home care, social day care, medical supplies, and counseling. Grants are offered as part of Care Consultation services, and fill a gap until a long-term care plan is in place. When Mr. Smaltz heard about the fund from Chapter Executive Vice President, Director of Programs & Services, Jed Levine, he realized how closely it aligned with his foundation’s mission. “I was impressed by the level of care and support provided by the New York City Chapter and the number of people served through your programs and services.”
Members of The Kelly Gang visited the NYC Chapter on June 15 to present a $60,000 contribution to Board Co-Chair Steven P. Casper. The Kelly Gang's annual fundraiser, held on St. Patrick's Day, supported the NYC Chapter's Caregiver Education and Training Program this year. The Kelly Gang will also be naming a Training Room on our third floor Program Center.  

(From left: Mike Kelly, Steve Casper, Keith Kelly and Ed Kelly)

Amir Perk (left), Vice President, and Daniel Poleshchuk, President of PACT (Public Awareness for Charity by Teens), both students at Stuyvesant High School, present a $2,000 donation to Jed Levine, NYC Chapter Executive Vice President, PACT partnered with NYC Rock to hold a charity concert, Alz Good, on March 20 to benefit the NYC Chapter. Amir and Daniel toured our Program Center, met with staff, and learned more about our work.

Graduates of the Chapter’s Dementia Care Training for Professional Caregivers in Spanish received certificates of attendance at a ceremony at the Chapter on June 24.

Graduates: Rita Maria Bautista Figueroa, Maria Blanco, Estela Bnazahan, Miriam E. Castaneda, Zoila Cordovez, Alicia Encalada, Juanita Fonseca, Crucita Heredia, Yaneth Jiménez, Mirla Jiménez, Karina Lucas, Yuderkis H. Martinez, Johanny Altugacil Mejía, Cecilia Moncercrate Mora Aguirre, Marisol Nieves, Katerina Marcia Quiróz, Carmen Ruiz, Angela Valdez
The Alzheimer’s Association, NYC Chapter invites you to the 28th Annual Chapter Meeting

Reducing Risk for Alzheimer’s in Your 20’s, 30’s and Beyond: What do we really know?

Moderated by award-winning broadcast journalist, Dr. Max Gomez

Monday, October 26, 2015

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

RSVP By October 20, 2014

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

www.alznyc.org/AnnualMeeting

Save the Date

Old Hollywood Gala
An Evening of Glitz & Glamour

A Junior Committee Gala benefiting the Alzheimer’s Association, NYC Chapter

Broad Street Ballroom
41 Broad Street
New York, NY 10004

Friday, October 2, 2015
9PM - 12:30AM

tickets go on sale Tuesday, August 11th

www.alznyc.org/glitzandglamour
Marking Milestones in May

Every once in a while you have the opportunity to experience something unusual, something one of kind, or even something spectacular. This May, the members of Athletes to End Alzheimer’s were able to experience this phenomenon… twice!

As always, the first Sunday of May commenced with the annual TD Five Boro Bike Tour. In the sea of almost 32,000 cyclists, a little over 30 athletes stood out as they fastened their helmets, zipped up their purple jerseys and hit the roads with their bikes on behalf of the Alzheimer’s Association, New York City Chapter.

On a crystal clear perfect day for riding on car-free streets, our Athletes cycled their way toward raising over $55,000 to support programs, services, and research. For one cyclist, this event signified an even greater milestone. Mike Schnitzer, who has fundraised for all five years of the team’s participation in this event, accomplished a lifetime goal by the culmination of the Bike Tour. Thanks to the generous support of friends, families, co-workers, and his company, Mike has personally raised over $100,000 for the NYC Chapter. What started in 2009 as humble goal to raise a little money and awareness in support of his father, Joel, turned into a personal mission to see an end to the devastating disease that wreaked havoc on his family, and ultimately took his father’s life. Mike, who was honored at the Chapter’s 2015 “Forget-Me-Not” Gala, would go on to say in his speech, “Do anything and everything that you can to bring awareness to this cause. Be creative, and be persistent. The end of Alzheimer’s starts with every one of us.”

Continuing the momentum from the Bike Tour, the players and coaches of Blondes vs. Brunettes® NYC (BvB™), took over the field with the mission to tackle Alzheimer’s at their fifth annual game under the lights on Roosevelt Island. On and off the field, the competition was fierce as both the BruCrew and the Blondetourage broke team fundraising records, raising over $83,000 and $110,000 respectively. All together the event set a new standard by raising over $200,000 for the Alzheimer’s Association. Additionally, a new BvB tradition was started with the first induction into the BvB NYC Hall of Fame, which acknowledges players and coaches that have raised over $10,000 in their BvB careers. Active players Kirsten Peissel, Elizabeth Irwin, Emily Bramowitz, and Elizabeth Johnson, in addition to alumni Lollie Britt and Tyndale Brickey, were acknowledged during a special ceremony at halftime, emceed by retired NFL players Jude Waddy, Hurvin McCormack, and Tony Richardson.

As the fourth quarter came to a close, after dramatic plays by both sides that kept all spectators on the edge of their seats, a victor finally emerged. Breaking a four-year drought, Team Blonde claimed its first win, snatching the trophy with a final score of 33-26. When all was said and done, new fundraising records had been reached and a new team held the trophy — but the night was not over yet. As overall top fundraiser and Team Blonde MVP, Kirsten, gave her post-game interview to the crowd, her boyfriend, active serviceman Ben Gibbs, dropped to one knee at centerfield and asked Kirsten to marry him (and become his MVP for life)! To many cheers and a few tears, Kirsten said yes, inviting the crowd of over 500 to witness one of the sweetest moments in BvB NYC history.

It was a great honor and privilege to be a part of these special milestones for our Athletes. These are the types of memories that they all fight to preserve when they join Athletes to End Alzheimer’s. Together we aim to share one larger major milestone, the end of Alzheimer’s.

Interested in joining Athletes to End Alzheimer’s? Visit www.alznyc.org/athletes or contact athletes@alznyc.org.
The Evolution of the Junior Committee

By Marielle Mindlin Bernstein
Junior Committee President

It is no secret that Alzheimer’s has the connotation of being “an old person’s disease.” Some call it “old-timers,” others equate it to senior citizens being senile. But, as anyone who has been affected by Alzheimer’s can tell you, it is anything but that. When a family member is diagnosed with Alzheimer’s, it affects the entire family. That is why, in the late 1980's, the Junior Committee (JC) was born; so that young professionals who had been affected by Alzheimer’s had a place to call home, a support system, and a vehicle to promote awareness and change.

Like most charity groups, the Junior Committee started small with a few people, an idea, and a vision. When Robert Wollin joined in 2001, there was a small core group of dedicated members. Shortly after joining the JC, Robert, who had just graduated from law school, helped define its structure by including an executive board and bylaws. The purpose of the Junior Committee outlined in those bylaws is what governs the JC to this day:

“The purpose of the Junior Committee is, as an organization of young professionals, to educate individuals in the 21-40 year age range about the devastating illness of Alzheimer’s disease. The Junior Committee seeks to raise funds to help promote an understanding of the disease among its constituents, contribute to funding research for a cure, educate healthcare professionals on the special needs of Alzheimer’s and related disorders patients, volunteer at Alzheimer’s patient facilities and Alzheimer’s Association events in the New York area and contribute to funding support groups for patients and their families.”

By 2002, Robert had become Treasurer of the Junior Committee, the distribution list had 60 members, and the JC had set up its own website. In 2015, having a website is not viewed as something to be proud of, but rather a regular part of life. However, back in 2002, getting a JC domain name, building a website, and having a place where any young professional could go to get information was pretty significant. The committee was hosting two fundraisers a year, one larger scale gala and one smaller happy hour, as well as volunteering with the community and participating in the Chapter’s lobbying efforts.

By 2008, Meghann McKale had been President of the Junior Committee for a few years, the distribution list had 150 members, and the annual gala had reached new heights with over 300 attendees and celebrity guests. The JC was also making its first strides towards a long time goal — securing bibs for the NYC Marathon. In 2009, while Erin Gabrielson was President, the JC formed its inaugural Run to Remember team for the NYC Marathon. The team had two coaches (both JC members), 55 runners, and raised over $337,000.

In 2011, the Junior Committee organized the first NYC Blondes vs. Brunettes® season, chaired by JC member Hili Banjo. The inaugural year raised over $110,000 and was the start of an annual event that would bring together dozens of young professionals to tackle Alzheimer’s. Shortly thereafter, the Chapter formed the Athletes to End Alzheimer’s (ATEA) program and grew both the marathon team and BvB game, along with other sporting events, into a fundraising program that raises hundreds of thousands of dollars each year. However, without the groundwork of the JC, the ATEA program may have never existed!

In 2015, the same founding principles guide the Junior Committee. Our distribution list has 750 members, our social networks reach thousands, our voices are heard in Albany and Washington, D.C., we volunteer directly with the community every month, we participate in ATEA events, and our annual galas have evolved and grown. Since its founding, not only has the JC raised over $2 million, it has been a home to so many young professionals who needed support, who needed an outlet, and who have influenced our generation to join the fight to end Alzheimer’s.
The Global Family Reunion took place on Saturday, June 6 to benefit Alzheimer’s disease!

Fun facts from the day:
- More than 3,700 cousins were on site
- Over 100 media outlets ran coverage
- Several world records were broken, according to Recordsetter.com, including Biggest Worldwide Family Reunion
Walk to End Alzheimer’s

This Walk is Personal

For the Alzheimer’s Association, New York City Chapter, the summer is when Walk season begins. For over 25 years, the Walk to End Alzheimer’s® has brought communities together to raise awareness and crucial fundraising dollars to support care, support, and research in the Alzheimer’s community. Every fall in NYC, thousands pledge to go purple and raise over a million dollars to support the local community and groundbreaking research.

The Walk is a joint effort by the Alzheimer’s Association, countless volunteers, dedicated community leaders, and, most importantly, the families and friends who literally bring our mission to the streets and parks of New York City. Less than a decade ago, we only walked in Manhattan, but every few years we steadily increased our reach to include the outer boroughs, with strong consistent turnouts in Brooklyn and Queens. And in 2015, expanding on the programs and services we already offer in the fine borough of Staten Island, we will grab our Promise Flowers and hop on the ferry with our inaugural Walk on South Beach.

Throughout the years the Walk has grown, and at the core of all of the success are our phenomenal teams and walkers. As we pause to reflect on the great history of the Walk, and prepare ourselves for another record-breaking season, we extend our gratitude to the thousands who have woken up early on Sunday mornings and joined us. And, because we know each Walk has its own distinct color, painted by the teams who join us, I’ll highlight inspiring team stories across all five boroughs.

BROOKLYN
Boardwalks, beaches, roller coasters, hotdogs, and that special Brooklynite spirit set the stage for our annual Brooklyn Walk to End Alzheimer’s. Embodying that spirit every year is Team Mighty Max, led by team captain and Sheepshead Bay resident Ingrid Posniack, who walks in support of her father Max, diagnosed with Alzheimer’s in his 60’s. Team Mighty Max, made up of family, friends, and members of the Jewish center where Max and his wife are very involved, started walking in 2010 and are consistent top fundraisers at the Brooklyn Walk. Earlier in his diagnosis, Max was able to join his mighty group at the Walks, but has since been confined to a wheelchair.

At last year’s Brooklyn Walk, in one of the special moments that Walk is famous for, Ingrid and her team were surprised and grateful when Max joined them in person, this time accompanied by residents of his assisted living facility and lovingly pushed in a wheelchair by his wife. This fall, the team will once again grab their purple T-shirts, take over the boardwalk, and continue the fight because their motivation, Max, and his spirit continue to inspire. As Posniack puts it, “I walk in honor of my dad. He is an incredible man. I almost said was, but he is still with us in body, although not mind.” Team Mighty Max will keep pushing forward until there is a cure.

MANHATTAN
Similarly dedicated and walking since 2007 is Harlem’s Rose Brunel and her team Williemaes’s Angels. When Rose’s mother, Williemaes Chiddick, was diagnosed with Alzheimer’s, Rose immediately turned to the Alzheimer’s Association to seek help preparing for her caregiving journey. She spoke with Chapter staff, attended education meetings, and eventually looked for an opportunity to give back to the Association and contribute to the overall mission to eliminate Alzheimer’s. The Walk to End Alzheimer’s in Riverside Park was a perfect fit for the children, grandchildren, and friends who still walk on the team. Williemaes, who passed away in 2013, was the consummate host and kept an immaculate home with an open door policy for her family. The Walk continues to be the type of event she would have loved. According to Brunel, every member of Williemaes’s Angels, from the oldest to youngest walkers, has a great time while always remaining “fully aware of why we are walking.” They join the greater NYC Walk family every year, now with Williemaes’s spirit guiding them to unite and be loud in support of our cause.

QUEENS
Celebrating its fifth anniversary at the site of the legendary World’s Fair is the Queens Walk to End Alzheimer’s. Drawing residents from all the tightly knit communities in...
the borough, this Walk has grown in both attendance and money raised, led for the past two years by top fundraising team Smiling Irish Eyes and their team captain, Thomas Bisighini of Middle Village. Teams come in all shapes and sizes; this one is small but mighty with only three members: Thomas, his wife Robyn, and his sister-in-law Terry. They walk in memory of Thomas’ mother, Pat Bisighini, a woman who was known and beloved for her kindness and truly embodied the team’s moniker, Smiling Irish Eyes.

Call it the luck of the Irish, but this team has had its share of challenges with the Walk each year. Their first year, Robyn was injured just before the Walk, requiring Thomas to push her in a wheelchair around the beautiful grounds of Flushing Meadows Corona Park. However, she was able to walk the last few feet to cross the finish line as the Thank You Brigade volunteers cheered. In 2014, Thomas suffered a third degree burn the day before the Walk and was in a hospital as the Walk dawned. Thanks to the marvels of modern technology, he was still able to watch the opening ceremony and, in his own words, experience the “amount of positive energy that surrounds Walk day and gives you the feeling that together we can conquer this disease.”

THE BRONX

While walkers can sign up individually, it’s always great to see an entire community come together to support a cause near and dear to their hearts. Such is the case for Team 291, whose members journey from the Bronx to join the Walk in Riverside Park. Started by the principal of P.S. 291, Carlos Velez, in memory of his grandmother Maria Castro, Team 291 has become one of the largest and loudest teams at the Walk in only two short years. The team members come from the entire school community, including administrators, teachers, parents, students, and families. As described by team member Rafael Sandoval, the Walk is “a family day, as all members bring their loved ones to be participants...[the Walk] became a community duty to honor those that we’ve lost, those who are living with the disease, and to celebrate those who provide care.

In 2013, after ten years under the loving care of Carlos’s mother, aunt, and uncle, Maria Castro lost her battle with Alzheimer’s disease. But from this tragedy, Team 291 emerged ready and eager to join the fight against Alzheimer’s. Together they embody the dual need to look back and remember those that have been lost while simultaneously looking forward to build a future full of civic-minded young people ready to step up to the plate and adopt this important cause as their own.

STATEN ISLAND

The Walk to End Alzheimer’s is an event in which participants honor memories, but also embrace the urgency to protect our futures. Taking this challenge to heart, Alexandra Gardiner, captain of Team Poppy, personally reached out to the NYC Chapter last fall. She knew the Staten Island community was missing the energy of the Walk, and she wanted to be a part of bringing it there. Fast forward to this fall, and our parade of purple will take over South Beach for the first time.

Team Poppy, who walks in memory of Alexandra’s grandfather Mario, has grown to over 20 people and will be the embodiment of Mario’s American dream. Mario came to the U.S. from Naples, Italy, as a teenager and became a business owner, avid soccer player with local clubs in Brooklyn, and family man. Joining Alexandra at the Walk this year will be Mario’s wife, children, and grandchildren. They will be among the teams cutting the ribbon at the inaugural starting line in Staten Island. They will join the thousands across this great city who walk in memory of those who are dearly missed and for the caregivers, whose, in Alexandra’s words, “continuous love, strength, and support should be celebrated.”

Alzheimer’s disease is a growing epidemic, and the numbers are startling. These statistics are important, but more important for those who participate in the Walk to End Alzheimer’s are the stories. When we say this Walk is personal, it’s because the Walk is about people. People like Max, Willemae, Pat, Maria and Mario, their legacies, and all the families who share similar stories. The Walk is about every New Yorker who is willing to use their words, their resources, their fundraising dollars, and feet to step up and say that they are ready to Walk until we END ALZHEIMER’S!

Interested in walking with us this fall? Go to www.alznyc.org/walk and sign up for a local walk!
When my mother first started exhibiting signs of cognitive impairment, I accompanied her to her primary care doctor’s appointment; the diagnosis – depression. Although that was in 1999, the experience would remain with me years later when my mother received an eventual diagnosis of vascular dementia and Alzheimer’s disease, known as mixed dementia.

Fast forward to 2010 when I became Manager of African American Outreach for the New York City Chapter of the Alzheimer’s Association. In this position, I was charged with the mission of educating the African American community about early warning signs of dementia, risk factors, treatments, and the services and programs available to them through the Alzheimer’s Association. It would be the memory of my mother’s initial diagnosis that would lead me to realize that part of this education process had to include the medical community as well as the general public. Physicians are oftentimes the first point of contact between families and persons with dementia and the trust issue is very present, especially within the older community.

So, the first initiative in my new position was to reach out to the African American medical community. That effort led to our ongoing collaboration with the Empire State Medical Association. This year marks our fifth collaboration: our annual African American Physician’s Dinner.

The dinner was held at the New York Academy of Medicine on March 25, 2015. Our speaker was Karen Bell, MD, Associate Clinical Professor of Neurology at Columbia University Medical Center’s Taub Institute for Research on Alzheimer’s Disease and the Aging Brain. Her presentation was titled Assessing Cognitive Impairment: An Approach for the Primary Care Physician. Dr. Bell’s presentation focused on the quick guide for primary care physicians available from the Alzheimer’s Disease Education and Referral Center, a service of the National Institute on Aging, and also addressed the benefits of early screening, brief screening tools, and resources. The Chapter’s own Medical and Healthcare Professional Outreach Manager, Gail Gallacher, spoke to the doctors in attendance about the Chapter’s screening resources and our rapid referral program.

As the number of Americans with Alzheimer’s disease continues to grow, primary care physicians continue to be the first point of contact for early detection and assessment. This is proof that the Chapter’s collaborative relationships within the medical community are necessary and valuable.

GreyMatters is an interactive life storybook app for the iPad that aims to improve quality of life for people with dementia and their caregivers. With a strong belief that people with dementia are “still here,” GreyMatters taps into the abilities that remain to keep individuals engaged and connected.

www.greymatterstous.com • info@greymatterscare.com
Follow @greymattersapp on Facebook & Twitter!
On April 29, the New York City Chapter was privileged to co-sponsor, along with the Quality Care Community (a partnership between the 1199SEIU Nursing Home Division and the Continuing Care Leadership Coalition) and the Center to Advance Palliative Care, a full day conference held at the Grand Hyatt titled Palliative Care for People with Dementia: Why Comfort Matters. More than 350 healthcare leaders attended, including representatives from nearly 30 nursing homes.

The day began with an enthusiastic kick-off by Shaywaal Amin, Vice President, Nursing Home Division 1199SEIU; Scott Amrhein, President of the Continuing Care Leadership Coalition; and Lou-Ellen Barkan, Chapter President & CEO. It continued with a panel discussion moderated by Jed Levine, Chapter Executive Vice President, Director of Programs & Services, which featured Dr. G. Allen Power, former Medical Director at St. John’s Nursing Home and author of *Dementia Beyond Drugs*, and Tena Alonzo, Director of Research and Palliative Care at the Beatitudes Campus in Phoenix, Arizona.

Highlighting the day were panel presentations by staff from each of the three nursing homes involved in the Chapter’s palliative care project: Cobble Hill Health Center, Isabella Geriatric Center, and The New Jewish Home.

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(From left: Shaywaal Amin, Janice Dabney and Scott Amrhein)  
(From left: Dr. G. Allen Power, Jed Levine and Tena Alonzo)  
(From left: Lauren Völkmert, Ed Cisek, Jane Ginsburg and Paula Rice)

The New Jewish Home Panel  
Cobble Hill Health Center Panel  
Isabella Geriatric Center Panel  
Opening Session
In 1906, German psychiatrist and pathologist Alois Alzheimer described the case of 51-year-old Auguste Deter, who exhibited progressive memory loss, language changes, and psychotic symptoms including hallucinations. An autopsy on her brain revealed atrophy and abnormal deposits in and around the nerve cells. In 1910, Emil Kraepelin coined the term “Alzheimer's disease,” which was regarded as a rare presenile dementia affecting those under 65 years old, distinct from senile dementia. Senile dementia was considered by many to be related to arteriosclerosis or hardening of the arteries. Little was written about Alzheimer's or senile dementia through the 1950's, and senile dementia was regarded by many to be a normal part of aging.

In the 1960's, advances in technology (e.g. the widespread use of electron microscopes) and cognitive testing (e.g. the Blessed Dementia Scale that quantified decline in daily activities) enabled scientists to identify a direct relationship between pathology in the brain (plaques and tangles) and dementia severity. In the 1970's, pioneering Alzheimer's research by neurologist Robert Katzman identified cell loss as the pathological characteristic that most related to dementia. The research also showed the brains of those with senile dementia had the plaque and tangles characteristics of Alzheimer's, suggesting that both conditions were part of the same disease process, and that it did not represent normal aging.

Important events and discoveries in the 1980's helped focus research, provide funding, and promote advocacy. The National Alzheimer's Association was founded in 1980 and the National Institute of Aging (NIA) initiated the first Alzheimer's Disease Research Centers, leading to the identification of two proteins, beta amyloid (associated with the development of plaques) and tau (associated with neurofibrillary tangles). There continues to be considerable debate as to how beta amyloid and tau contribute to the development of Alzheimer's disease (AD). Early research focused on cholinergic deficits and their relationship to cognitive decline, which in turn led to the development of several FDA-approved medications to treat the symptoms of AD, the first of which was approved in 1993. These include the now discontinued tacrine (Cognex), donepezil (Aricept), rivastigmine (Exelon) and galantamine (Razadyne). Memantine (Namenda), which regulates glutamate, was approved in 2003 and Namzaric, a combination of memantine and donepezil was approved in 2014.

In the 1990's, researchers identified several genes (Presenlin-1, Presenlin-2 and APP) believed to cause many cases of the early-onset (before age 60) form of AD. In fact, it is now believed that Auguste Deter had this mutation. They are referred to as “deterministic” genes because the presence of these genes directly causes AD. The NIA's Dominantly Inherited Alzheimer's Network (DIAN) study examines families from around the world who have the genetic mutations that cause early-onset AD. Other genes have been identified as “risk” genes, including apolipoprotein E-e4 (APOE-e4). The presence of these genes increases the risk of developing the more common late-onset AD. Large-scale studies including the Genome-Wide Association Study (GWAS) and the Alzheimer's Disease Genetics Study allow researchers to identify new genes that cause AD. Additionally, the Nerve Growth Factor (NGF) trial is a novel study that uses gene therapy to deliver NGF directly to a specific part of the brain, via surgery, to determine if NGF can help cholinergic neurons survive.

While MRI and CT scans have been used for many years to aid in diagnosing AD and ruling out other causes of cognitive decline, neuroimaging techniques such as FDG-PET, SPECT, and amyloid imaging have become more sophisticated and are powerful research tools. In 2005, the large-scale Alzheimer's Disease Neuroimaging Initiative (ADNI) study began. The purpose of this study is to better understand the use of biomarkers, including neuroimaging, cerebrospinal fluid and blood tests, in research trials and to diagnose and monitor AD. In 2012 the FDA approved flortiapir (Amyvid). Flortiapir binds to and highlights amyloid plaques in the brain so they can be seen in a positron emission tomography (PET) scan. The scan is primarily used for research purposes, but may be covered in the future by health insurance if it proves useful.

The idea of using the body’s own immunity with an “Alzheimer's vaccine” to combat amyloid buildup has great appeal, but the first clinical trial was terminated in 2002 after some participants developed an allergic inflammation of the brain. Subsequently, some researchers turned to immunotherapies that rely on passive immunity, where anti-amyloid antibodies are created in a lab and infused into patients, against amyloid plaques. While several recent Phase III trials have yielded disappointing results, other second generation active vaccines and passive immunotherapies are currently being studied.

In the past two decades, research focus has shifted to earlier stages of the disease. This includes studying those with Mild Cognitive Impairment (MCI), thought to be a prodromal stage of AD and characterized by the presence of objective cognitive difficulties measured by paper and pencil tests, that does not yet interfere with daily functioning. Very recently, scientists have discovered that the disease process, measured by biomarkers, can begin decades before symptoms appear. These findings have prompted prevention studies that aim to determine if certain medications might stop or delay the onset of AD in those who have no symptoms but are at high risk for developing AD. Current studies include the A4 and Tommorow trials, which are recruiting “high risk” individuals that have amyloid buildup in the brain or genes that may predispose them to developing AD.

There is significant interest in identifying effective strategies to help caregivers manage the burden of caring for someone with AD. Some interventions include skills training, counseling, respite care, and social support. Studies suggest interventions may not only reduce caregiver burden and depression, but may improve outcomes for patients, such as reduced behavioral disturbance and delay in needing nursing home placement.

Considerable scientific progress has been made in the last 30 years and advocacy efforts have helped educate the public and secure funding. Finding a cure for AD is dependent on well-designed and executed studies, significant funding and, equally important, volunteers to participate. Learn more by contacting one of the three local Alzheimer's Research Centers that comprise NYCARE or visit Alzheimer's Association TrialMatch® at alz.org/trialmatch or 1-800-272-3900.
Why Do **YOU** Read Our Newsletter?

The newsletter has undergone many changes over the past three decades, and year after year more and more of you read it. We decided this would be a great time to find out why.

Sure, we hear occasional feedback from people we meet at a health fair or who attend a Family Caregiver Workshop, but as Vice President, Director of Program Evaluation at the Chapter, my job is to systematically investigate our programs and services…and now our newsletter.

So, we created a survey, sent it to a sample of people who have had recent contact with the Chapter, and analyzed the results. We heard from over 200 of you! Survey respondents were connected to the person with dementia in one of three ways (see Figure 1).

Here’s what we learned:

1. There is no clear preference for the print or online version of the newsletter (see Figure 2).

2. In your own words, you told us the newsletter benefits you by:
   - Keeping readers informed about Chapter programs, activities, and events
   - Providing practical caregiving tips
   - Helping caregivers feel connected to other caregivers
   - Updating readers about research

3. Many of you share the information you learn from the newsletter with others. Please keep it up!

4. Though readers are very satisfied with the newsletter, you have some great ideas of what to include in future issues. As a result, as one of our survey respondents suggested, from now on you will have the opportunity to provide feedback any time you want.

Through our new Tell Us What You Think link, you can let us know what you liked or disliked about the issue, and what you’d like to see in future issues. Simply go to www.alznyc.org/feedback.

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**Send us your newsletter feedback!**

www.alznyc.org/feedback

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**Figure 1. Reader’s relation to person with dementia**

**Figure 2. Reader’s preferred format**
**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:**
- August 6: Noon - 2:00 p.m., Queens
- August 11: 5:30 – 7:30 p.m., Manhattan
- August 14: Noon – 2:00 p.m., Manhattan
- August 19: 1:00 – 3:00 p.m., Brooklyn
- August 19: 5:30 – 7:30 p.m., Manhattan
- August 26: 6:00 – 8:00 p.m., Upper Manhattan
- September 3: 12:30 – 2:30 p.m., Queens
- September 8: 5:30 – 7:30 p.m., Manhattan
- September 11: Noon – 2:00 p.m., Manhattan
- September 16: 5:30 – 7:30 p.m., Manhattan
- September 16: 6:00 – 8:00 p.m., Brooklyn
- October 1: 12:30 – 2:30 p.m., Queens
- October 9: Noon – 2:00 p.m., Manhattan
- October 13: 5:30 – 7:30 p.m., Manhattan
- October 21: 1:00 – 3:00 p.m., Brooklyn
- October 21: 6:00 – 8:00 p.m., Manhattan

**Upcoming Dates Just for Professionals:**
- September 9: 3:00 – 5:00 p.m., Manhattan

**Upcoming Dates in Spanish:**
- August 12: 5:30 – 7:30 p.m., Upper Manhattan
- November 11: 5:30 – 7:30 p.m., Upper Manhattan

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

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:**
- September 15: 5:30 – 7:00 p.m., Manhattan
- October 20: 5:30 – 7:00 p.m., Manhattan
- November 17: 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:**
- August 6: 5:30 – 7:00 p.m., Manhattan
- August 11: 5:30 – 7:00 p.m., Manhattan
- September 21: 5:30 – 7:00 p.m., Manhattan
- September 24: 5:30 – 7:00 p.m., Manhattan
- October 5: Noon – 1:30 p.m., Manhattan
- October 19: 5:30 – 7:00 p.m., Manhattan
- October 22: 5:30 – 7:00 p.m., Manhattan

**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:**
- September 3: 5:30 – 7:00 p.m., Manhattan
- October 1: 5:30 – 7:00 p.m., Manhattan
- November 5: 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 Educational Meetings
Upcoming Dates (all meetings from 6:00 – 8:00 p.m.):

August 10
Family Conflicts in Caregiving
• Recognizing different styles of communication
• Understanding the role of mediation services and setting appropriate boundaries
Speaker: Ana Araujo, LMSW, Care Consultant
Lauren Volkmer, LMSW, Manager, Early Stage Services

September 21
Creating Meaningful Activities
• Understanding meaningful activities
• Modifying activities for each stage of the illness
• Learning how to use what you have
• Understanding how our approach can affect the outcome
Speaker: Nancy Hendley, MFA, Dementia Care Trainer

October 19
Managing Challenging Behaviors
• Defining behaviors: Is it a problem? For us or them?
• Understanding potential causes of behavior changes
• Strategies to adapt and adjust our response
Speaker: Amy Torres, Manager of Training

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.

For more information, please call our 24-hour Helpline at 800-272-3900.

We ask that you notify us to reschedule whenever you cannot attend a seminar for which you have registered.

Classes often have waiting lists, which we cannot accommodate unless we know of absences. Thank you for your cooperation.

Looking to hire home care workers trained by the NYC Chapter of the Alzheimer’s Association?

Together We Care™ can help in your search.

www.TogetherWeCare.com
Connecting trained home care workers with the families who need them.

The NYC Chapter of the Alzheimer’s Association trains hundreds of home care workers each year through our nationally-recognized Dementia Care Training for Professional Caregivers program.
TogetherWeCare.com provides you with the opportunity to view profiles created by graduates of our training program, or create your own ad.

Join for free today.
www.TogetherWeCare.com

Connect2culture is a cultural arts program, supporting museums and other cultural venues in developing ongoing programs for people with dementia and their caregivers. Visit this website to learn about upcoming programs in your area www.alznyc.org/connect2culture.

An announcement about the free publications we offer online, www.alznyc.org/publications, or via printed copy on request:
• Easing the Transition: Moving Your Relative to a Nursing Home (English, Spanish, Chinese)
• Making Home Care Work For You Guide (English, Spanish, Chinese)
• Family Caregiver Guide (English & Spanish)
THE END OF ALZHEIMER’S STARTS WITH you.

Sunday, September 20
Flushing Meadows Corona Park, Queens

Sunday, September 27
South Beach, Staten Island

Sunday, October 4
Coney Island Boardwalk, Brooklyn

Sunday, October 18
Riverside Park, Manhattan

www.alznyc.org/walk
24-hr Helpline 800-272-3900