New York City Chapter

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### Date
- **Fall 2014/Winter 2015 Calendar**
President’s Message

Dear Friends,

When we decided that the theme of this newsletter would be “Chapter Expansion,” I immediately thought of the famous quote from Field of Dreams, one of the great baseball movies of all time. To paraphrase: “Build it and they will come.”

Odd as it may sound, the experience of Ray Kinsella, the Iowa corn farmer portrayed by Kevin Costner, who hears a voice and is inspired to build a magical baseball field in the middle of nowhere, is pretty similar to what happened here at the NYC Chapter – the cornfield notwithstanding.

In the last 18 months, with the support and incredible generosity of our Board and other benefactors, the Chapter has undergone a great expansion. We doubled our capacity – growing to more than 30,000 square feet. We opened the state-of-the-art Harry and Jeanette Weinberg Early Stage Center that offers new programs and activities for individuals in the early stage of dementia, their care partners and family members. We expanded in Brooklyn and Queens – with satellite offices in both boroughs serving people who cannot travel because of their demanding caregiving responsibilities, their own disabilities, or a discomfort with leaving their neighborhood.

Like the visionary Iowa corn farmer, we did this on a leap of faith. We had no surveys or studies to prove that the demand for Chapter services would grow. We did have growing waiting lists of clients for many of our programs and services. And we knew that there were more than 500,000 people in New York City’s Alzheimer’s community – either people with the disease or their caregivers – and that only a fraction of them was getting the help they needed.

Since our expansion, new calls to our 24-hour Helpline – often the point of entry for people who remain our clients for a decade or more – are up 111%. Registration in our MedicAlert® Foundation + Alzheimer’s Association Safe Return® program has increased 35%. Total enrollment in our workshops and educational programs has skyrocketed by 30%. Our Harry and Jeanette Weinberg Early Stage Center is fast becoming an important second point of entry for new clients. And the number of people we serve in Brooklyn and Queens is up thanks to the borough-based offices.


There are many factors that have contributed to this explosion in program utilization at the Chapter. First, Alzheimer’s is no longer in the closet. A steady stream of national media stories about dementia has forced the public to pay attention to our nation’s third largest killer.

Second, a chorus of strong voices now speaks for Alzheimer’s. Brave individuals who have the disease – like former University of Tennessee women’s basketball coach Pat Summitt, country singer Glen Campbell and world renowned restaurateur B. Smith, as well as advocates like David Hyde Pierce, Seth Rogen and Kimberly Williams-Paisley – have catapulted Alzheimer’s into everyday conversation.

Third, people in the Alzheimer’s community are in dire need of support and they are speaking out and showing up at our walks, our conferences and our programs in growing numbers.

Finally, and most significantly, from that first desperate call to our 24-hour Helpline, to the dreaded and difficult end of life decisions, the quality, continuity, diversity, and expansive continuum of care we provide at the Chapter has no equal. Let me be clear, it’s one thing to search the internet for help, but quite another to walk into the Chapter offices and immediately feel safe and supported, knowing that you are in the hands of caring and compassionate professionals who will be there for you as long as you need them.

In the ten years that I have been in this job, I have yet to meet a single person who doesn’t end their first Chapter visit by saying, “I’m so glad I made the call!” Please, if you need help or you know someone who might, make the call now at 800-272-3900.

As Dr. Archibald “Moonlight” Graham (Burt Lancaster) said in Field of Dreams, “This is my most special place in all the world. Once a place touches you like that, the wind never blows so cold again.”

We have built it. Now, will you come?

P.S. Please see our Year-End letter on page 17. We hope you will support us so we can continue to expand our services to reach all who need us in New York City.

Lou-Ellen Barkan
President & CEO
LBarkan@alznyc.org
Dear Readers,

After almost 25 years as a staff member at the Chapter, I have seen enormous growth in the range, scope and breadth of our services. When I was hired in 1990, I could count the number of staff on two hands. Now that we are close to 60 staff members, our ability to serve the needs of persons with dementia, their families and professional caregivers has grown along with a demand for services.

This is a time to reflect on the past, assess the present and plan for the future. In that spirit, I offer the following thoughts:

We have grown from a dedicated base of volunteers answering the helpline to a professional staff of specialists and counselors who are responding to over 800 calls a month. Last year alone, as we responded to over 4,000 new callers, we continued to explore ways to improve our 24-hour Helpline operation, making it even more responsive to the growing number of callers.

Our MedicAlert® Foundation + Alzheimer’s Association Safe Return® Program was launched in response to a tragic loss of one man with early onset/early stage Alzheimer’s who disappeared on his way home from tutoring a child in school. Today, we have over 21,000 New Yorkers enrolled in the program, enjoying the protection and security of the system.

Our training and education programs have grown significantly with the addition of four trainers, reaching families in every corner of the city. The Family Caregiver Workshops and Dementia Care Training for Professionals are routinely filled to capacity. The addition of dementiaaides.org allows us to bridge the gap between families looking for in-home care and home care workers looking for employment.

Our support groups, always a lifeline for family members, continue to thrive, as we strengthen the connection between support group leaders, the Chapter, and the families we serve.

Early Stage Services have grown too. In 1990, an individual with early stage Alzheimer’s asked, “what do you have for me?” So, we piloted a support group for persons with early stage Alzheimer’s, and had an occasional field trip to one of New York’s cultural institutions. Two years ago, to meet the growing demand, we opened The Harry and Jeanette Weinberg Early Stage Center, a vibrant, thriving place of connection, support and innovation in early stage programming.

I am very proud that our Diversity and Inclusion programs ensure that all New Yorkers have access to our programs and services in a language and cultural voice that is both comfortable and familiar. We have made huge strides in reaching the Latino, African American, Chinese, Russian, Korean, LGBT and Orthodox Jewish communities.

One of the consistent challenges for the Chapter has been engaging doctors and other healthcare professionals. We now have materials, tools and a full-time staff member whose sole responsibility is to get the word out; to let the medical community know that we are here, and can help them deal with the non-medical challenges of Alzheimer’s.

Among our many special projects, one stands out: Comfort Matters™, a new model of palliative care for residents in NYC’s nursing homes. In the residential care arena, which often seems intractable and devoid of hope, we have learned much that will change the lives of so many residents, family members and staff.

Finally, over the last few years, we have significantly raised our profile in the halls of government, ensuring that Alzheimer’s is a priority in City Hall, Albany and Washington, DC. The number of our advocates continues to grow. We must carry on this effort to both increase research funding and ensure that caregiver supports are available.

As the Chapter grows, we remain true to our core value of providing information, care and support to families coping with this disease. Families facing Alzheimer’s often feel helpless, hopeless, confused, and frightened. The treatment for AD remains modest, and the pace of research is disappointingly slow. But in the absence of an effective therapy, good care is the best treatment. We have learned so much about caring for the person who has the disease and for the caregiver.

Let us help you or anyone who needs our help. Give us a call at 800-272-3900 or visit us on our website at www.alz.org/nyc.
This installment of Chapter in the News starts off with an exciting announcement that Lou-Ellen Barkan, Chapter President and CEO, has been invited by the Huffington Post to host her own blog page on the site that attracts almost 49 million readers every month.

Lou-Ellen’s first essay on the Post 50 blog took an interesting look at “The Unexpected Face of Alzheimer’s”. It examined a set of statistics and the compelling stories of caregivers, people with the disease and researchers. She wrote, “In the end, facts and figures do matter. Numbers compel politicians to action. Numbers drive research dollars and resources for care. But it is the face of Alzheimer’s that will forge change. The more active our community becomes, the more visible we are and the stronger our voice, the harder it will be for elected officials, policy makers, corporate America and the voters to ignore us.” Please be sure to check her blog page periodically for new and compelling posts.

Who needs an ice bucket challenge? In June, the Chapter launched our own creative awareness campaign called Dyeing to End Alzheimer’s, challenging our supporters to dye their hair purple in a show of support for the Alzheimer’s community. On June 20, dozens of family members, staff and supporters – including actor David Hyde Pierce – gathered in Central Park and answered the call, sporting purple hair and wigs. The event was well covered by the media with stories and photos appearing on WCBS News (channel 2), FOX 5, WPIX (channel 11), Getty Images, and BroadwayWorld.

The Chapter’s MedicAlert® Foundation + Alzheimer’s Association Safe Return® Program also made headlines over the past few months. Telemundo, the Spanish language network, did a significant story on wandering tied to a missing person with dementia in Brooklyn. The Chapter’s own Elizabeth Bravo Santiago and Alejandro Berti were featured in the story. Jed Levine, the Chapter’s Executive Vice President and Director of Programs and Services, was also featured in two Times Ledger stories on the topic. The first focused on a specific missing person case in Queens, and the second on the larger problem of wandering, as well as the benefits of the lifesaving Safe Return Program.

In fact, the Chapter has recently kept Queens reporters very busy! You may have also read about the Chapter’s exciting expansion into that borough. New services for thousands of people with Alzheimer’s disease and their family caregivers will now be available to residents of Queens, right in their own communities thanks to a grant from the Stavros Niarchos Foundation. Stories about the expansion were published in the New York Nonprofit Press and the Queens Chronicle, while the Chapter’s new Queens Care Consultant, Yungae Yook, was featured in a Crain’s New York Business item.

Times Newsweekly, another Queens news outlet, included a story about An Evening Ride on the Forest Park Carousel to End Alzheimer’s – the third annual Chapter fundraiser hosted by New York Carousel Entertainment, LLC. The story also included information about the Walk to End Alzheimer’s in Flushing Meadows Corona Park, Queens, held on September 28.

In addition to the New York Times coverage of the Forget-Me-Not Gala, which we told you about in the last newsletter, the Gala was also featured, in word and photos, in Crain’s New York Business, New York Social Diary, New York Nonprofit Press and Azureazure.com.

Most recently, the Junior Committee of the Alzheimer’s Association, New York City Chapter held their Speakeasy Soiree on September 19, raising over $60,000 for the Chapter. Bill Cunningham attended the event and it was featured in his Evening Hours column in the New York Times Sunday Styles section.

From the New York Times to CBS New York, and from Newsday to Hamptons.com, Chapter events like our Brain Awareness Summit, the Walk to End Alzheimer’s in Brooklyn, Queens, and Manhattan; educational workshops for the Latino community, and the Junior Committee Gala have all been featured in community calendars that keep New Yorkers informed about important events in their local communities.
Over the years, our President & CEO, Lou-Ellen Barkan, has interviewed a number of people for our newsletter. Now, in the year of her 10th anniversary with the Chapter, she sat down with Executive VP, Director of Programs & Services, Jed Levine, and Senior VP of Development & Director of Leadership Giving, Carol Berne, to share her thoughts.

**Jed Levine (JL):** Congratulations on your 10-year anniversary with the Chapter! Can you tell our readers what brought you here?

**Lou-Ellen Barkan (LEB):** My father had Alzheimer’s and my mother was a caregiver for over 12 years. I thought about all the families, like ours, who could benefit from resources that the Chapter offers.

So when someone proposed that I go back to work, after I retired, my first thought was that it would have to be something that was personally important to me, in order to do the work with my whole heart.

**JL:** You’ve spoken very openly about your parents. Can you talk about how they affected your understanding of the Chapter’s work?

**LEB:** I thought I knew a lot from watching my mom’s caregiving experience, but when she got sick, I suddenly became the person who was in charge and I realized I didn’t know everything. I was lucky enough to have the option to go directly to our Director of Caregiver Services, Matt Kudish. I sat in his office just like any other anxious, exhausted caregiver and tried to understand what I needed to do to help mom and myself. It was an extremely challenging time and it dramatically changed my perspective on what our clients really need and how to deliver these resources.

I’ve often said that it gave me pause to think about what it feels like to be someone in the same position, but doesn’t speak English as a first language, doesn’t have the resources or a personal network, doesn’t have a business background or a family. It’s hard to imagine, and the desire to help these families makes it easy to get out of the bed in the morning to do my job.

**JL:** What is your vision for the next few years?

**LEB:** First, to expand on the work we’ve done reaching out to NYC’s diverse communities. We’ve made progress in focusing on the Latino, African American and Chinese communities, but there are so many more that need our help.

Second, while we are always striving to do our best, we need to set the same example for our community partners. Not everybody has our resources, but it’s our job to set the standard and help others try to reach it.

Finally, given the scope of the problem, we’ll have to continue to build our team, not just in terms of numbers, but in terms of expertise. We’ve established a unique business model; hiring young professionals and helping them develop their careers. But to be effective, we need to have seasoned professionals willing to train and mentor the younger staff.

**JL:** We’ve accomplished so much in the past 10 years. Really extraordinary growth, serving more people, greater variety and breadth of programs, more sources of funding and greater relationships. What are the things that you are most proud of as you reflect on the past 10 years?

**LEB:** When I got here, I was surprised to see that there were a lot of volunteers doing work that I thought should be done by professionals. So
Reflections

one of my first questions was how to professionalize the staff to meet the demands of the future. Today, I am so proud that we have accomplished that goal. We still have many great volunteers doing terrific work for us, but our core staff is a solid group of professionals.

Today, our impact is a lot bigger than our footprint because our professional staff understands the value and impact of community relationships. There’s no way, given the scope of this disease, that we could do all this ourselves. The goal has always been to collaborate with every institution, every individual who has the capability to add value to our work. So I’m the proudest of our partnerships and of the staff’s capacity for building, developing and sustaining those partnerships.

Also, I’m always very proud that when we walk into a room, people know us and they know our team and what we can deliver. In a city as big as this one, it’s a wonderful way to know we’re achieving our goals.

JL: One of things that you’ve been most successful at has been developing and engaging our Board. How did you go about that?

LEB: What made it easier is that most Board prospects come to our door because they have been through the disease with a family member. They know and understand the challenges. We wanted a committed group of individuals to be investors in our work, with an interest in directing resources in ways that would help others.

Boards develop as individuals come and go. The real challenge is making sure these seats are always filled with the right people. Keeping a strong and supportive Board has always been my first priority and, to date, we’ve been very lucky.

Carol Berne (CB): What has the role of fundraising played in helping to achieve what we have now, as well as achieving hopefully the vision of the future?

LEB: Creating a business model where fundraising is front and center was the first goal I had when I got here and the most important first step was building trust between the fundraisers and the program staff. In a perfect world, our program staff would understand their role in raising funds and our fundraisers would understand our programs.

CB: What do you enjoy about fundraising?

LEB: I love explaining why this is a great organization for others to support. I love to tell the story of all the great work we do and I love when people say: “Yes, Yes, I’d like to join your Board.” “Yes, I’d like to buy a ticket to your Gala.” “Yes, I would like to make a meaningful contribution.”

Even better is the day when I can bring them here and show them what we’ve done with their funds. That’s real satisfaction.
My aunt has attended MemoryWorks® at the NYC Chapter’s Early Stage Center and now her illness has progressed to the point where she can no longer attend programs at your center. She would still like to remain involved with outside activities in the community, but, understandably, they must be appropriate for her situation. What is available for her now? -Susie

Dear Susie,

It is wonderful that your aunt has been able to take advantage of our programs through our Harry and Jeanette Weinberg Early Stage Center, which aims to provide a supportive environment through specialized programs for people with early stage dementia.

Now that your aunt’s dementia has progressed, there are a number of options for the family to explore and consider. There is a limited number of programs in the city for people who are transitioning between the early and middle stages that our 24-hour Helpline staff can discuss with you.

As she continues to move through the stages of the disease, your aunt may benefit from a social adult day program. These are programs designed to provide care outside of the home to meet someone’s needs while supporting strengths, abilities, and independence. Participants have the opportunity to interact with others in a structured environment. Adult day programs offer cognitive stimulation and some even offer music, art and other recreational activities as well as assistance with ambulation, toileting, specialty meal preparation, and feeding. Depending on the program, staff may be onsite to provide clinical services such as medication administration, personal care assistance, and case management services. Typically, programs are open daily during regular business hours, sometimes on the weekends. Most offer lunch and a snack. Transportation is often provided but may be limited to their surrounding neighborhoods.

Another option is home care, which is supportive care provided in the home of the person with dementia. Home care allows people to remain in the comfort of familiar surroundings throughout the course of their disease and provides one-on-one opportunities for engagement and socialization. Home care services include personal care, household chores, and health care. Home care can be obtained for a wide range of hours, from four hours a day up to 24-hour care. Some insurance plans will pick up the cost of home care, and you can also pay privately.

The home care worker can also bring your aunt to connect2culture® events. connect2culture® offers people with dementia opportunities to engage in arts and culture programs at museums and other cultural institutions throughout the city. The NYC Chapter hosts We Sing & Dance!, a sing-along and ballroom dance program for persons with dementia and their caregivers, throughout the year. This program is facilitated by our Dementia Care Trainers and other staff who, along with ballroom dancers from Rhythm Break Cares, sing and dance to favorite songs.

Keep in mind that as your aunt’s disease progresses, the Chapter also offers programs and services to meet your needs. Our Family Caregiver Workshop is popular among people caring for relatives with Alzheimer’s disease. The Family Caregiver Workshop is a 10-hour series which focuses on a person-centered care approach in a supportive and nonjudgmental environment. This Workshop was designed to improve the quality of life of both the caregiver and the person with dementia.

The goals of the Workshop are to:

- Provide knowledge about Alzheimer’s disease and related dementias and insight into the thoughts and experience of the person with the disease.
- Assist caregivers in developing practical skills to enhance ongoing communication.
- Present ways to understand the behaviors often associated with dementia and helpful strategies for managing them.
- Encourage self-care.
- Offer information about available resources.

These Workshops serve as wonderful opportunities for family members to meet other caregivers who are in similar situations. We offer these Workshops at a variety of times in order to accommodate diverse schedules of caregivers. For schedules and to register, please call our 24-hour Helpline at 800-272-3900. If you are unable to attend the Workshop, you may want to read our Family Caregiver Guides. We recently updated our Guides to ensure that the information is accurate, concise, and aligned with our newly developed Family Caregiver Workshop curriculum.

You may also want to consider joining a support group. We offer approximately 125 groups throughout the five boroughs. A 24-hour Helpline Associate can provide you with support groups near you.

I encourage you to continue to work with the Chapter as your aunt’s disease progresses. We are here to provide you with support and assistance and are available around the clock, 365 days a year.
People move into and out of our lives on a regular basis and for a variety of reasons. One of the most amazing elements of these connections, brief or longstanding, is that you often never know at the onset of a relationship just how important a person will become to you or how significant an impact he or she will have on your life.

When Marie and Celia became friends more than 15 years ago, neither could have imagined how important the other would become in their life, especially in the face of a diagnosis of Alzheimer's disease.

Marie and Celia were introduced through a mutual friend. They quickly bonded during the excursions that Marie would plan for their group of friends, including trips to the theater, restaurants, and out of town. But the depth of this friendship, built on mutual trust and respect, was never so evident as when Celia, nearly two years ago, shared with Marie that she could no longer tolerate the abusive relationship in which she was involved. Marie immediately jumped to help her friend, inviting Celia to move into her home.

Unfortunately, the difficulties that Celia had been experiencing did not end there. Now that Celia was living with her, Marie began to notice the problems Celia was having with her memory. Not only did Celia become lost on her way home from work, compassionate colleagues reached out to Marie to tell her that Celia was becoming unable to function at work.

Eventually, Marie arranged for Celia to visit a neurologist who diagnosed early-onset Alzheimer's disease, as she was only 50 years old. With the support of Marie and her workplace, Celia was respectfully transitioned out of her job and onto short-term disability benefits.

Marie worked to enlist the help and support of Celia's family, all of whom lived out of state. But none were able to accept the responsibility of caring for her. Unwilling to abandon her friend in her greatest time of need, Marie made the commitment to become Celia's primary caregiver, doing whatever necessary to ensure that not only were Celia's needs met, but also that she was provided with the best quality of life possible. It was a life-changing decision.

With no experience caring for a person with dementia, Marie jumped into a world of never-ending responsibilities that required her to navigate systems she never knew existed.

Thankfully, Marie contacted the Chapter to find support. Working with a social worker in our Early Stage Services department, Celia connected with a program close to home for individuals with early-onset Alzheimer's disease. Marie then met with a Care Consultant at the Chapter for guidance on managing the necessary financial tasks to ensure Celia's long term well-being, including applying for Social Security disability insurance and Medicaid health insurance. Marie attended our Understanding Dementia Seminar and participated in our Family Caregiver Workshop so that she could learn more about what to expect as Celia's condition progressed and how to make necessary adjustments to her care.

Marie knows that it takes a village to care for Celia, and she has been grateful for the support and assistance of her own family, who have welcomed Celia as one of their own. Marie and Celia also have the support of several of Celia's long-time friends and colleagues, who still visit and enjoy time together.

Yet Marie also knows that eventually the current village won't be enough to give Celia the care she needs to ensure the quality of life that she deserves. As such, Marie continues to work with the Chapter to explore options for Celia's future.

Despite the challenges that Marie has experienced in wholeheartedly accepting the responsibility of caring for her friend, she has been enriched by the perspective it has provided and the patience she has learned to must practice. Marie and Celia continue to enjoy their time together, going to concerts, attending barbeques, and celebrating at birthday parties; in other words — living. Neither Marie nor Celia, when they first met, could have imagined the journey on which their relationship would take them, but clearly their lives would not be the same without each other. Theirs is a friendship to be celebrated.

To learn more about Care Consultation, or to schedule an appointment, call our 24-hour Helpline at 800-272-3900.
Dreams are turning into reality. The Alzheimer’s Association, New York City Chapter, is proud to share that we are expanding the scope of programs and services we deliver throughout the five boroughs.

Our initial expansion began in Brooklyn in 2012 when the Chapter hired a full-time Care Consultant to work out of the Brooklyn Alzheimer’s Disease Assistance Center at SUNY Downstate. Recently, a generous grant from the Stavros Niarchos Foundation has enabled us to expand even more deeply into Brooklyn, as well as into Queens.

Today, more of our programs and services are available in Brooklyn than ever before. Our education seminars are growing rapidly in the borough. We recently hosted our first Legal & Financial and Medicaid Home Care Seminars and next month we will offer our Placing Your Relative in a Nursing Home Seminar. A growing number of caregivers attend our monthly Understanding Dementia Seminar offered in collaboration with Heights & Hills. We are also pleased to report that our Family Caregiver Workshops have been offered in three different locations across the borough. Brooklynites are also encouraged to participate in our connect2culture® programs, register for MedicAlert + Alzheimer’s Association Safe Return® and take advantage of our Care Consultation services right in their own backyards.

For more information regarding Care Consultation in Brooklyn, please contact Lorna Walcott-Brown at 718-287-1124 or at LBrown@alznyc.org.

The Stavros Niarchos Foundation’s generous grant has also afforded us the opportunity to hire a bilingual English and Korean speaking Care Consultant to provide individual and family counseling sessions at three different locations in Queens. We also offer our Understanding Dementia Seminar, Family Caregiver Workshops and connect2culture® events in Queens. Our plan is to begin to bring even more of our education and training programs into Queens over the next several months. For more information regarding Care Consultation in Queens, please call Yungae Yook at 917-675-1445 or at YYook@alznyc.org.

It’s only a matter of time before we are able to offer all of our programs and services in each of the five boroughs, which is our long-term goal. In the meantime, all New Yorkers can take advantage of our full array of programs and services at our Chapter office, and across the city through our robust network of community partners. It is exciting to report these “small” steps of our journey. We look forward to marching along and continuing to explore opportunities to expand. For more information about any of our free programs and services, or to tell us what you’d like to see in your neighborhood, please call our 24-hour Helpline at 800-272-3900.

Looking to hire private home care workers?

DementiaAides.org can help in your search.
Brooklyn & Queens Expansion

The NYC Chapter is the city’s central hub for information, education and support involving Alzheimer’s disease and related dementias. Our goal is to serve everyone affected by dementia across New York City in the most culturally and linguistically competent manner possible.

Tens of thousands have come through the doors of our midtown Manhattan headquarters to attend education meetings and caregiver trainings, participate in our early stage center, and take part in support groups. And we are seeing record numbers of attendance at similar programming offered throughout the boroughs.

Still, we wanted to do more. Our dream is to have a location in each borough. Our first opportunity to do so came in 2012 when we learned that a long standing partner, SUNY Downstate’s Brooklyn Alzheimer’s Disease Assistance Center (BADAC), had lost the funding for a key staff person. Lorna Walcott-Brown has worked at the BADAC for nearly 20 years, providing social support for clients and families. The Chapter understood the value and importance of this resource. Lorna joined the Chapter as a Care Consultant and continues to support those affected by dementia in Brooklyn, working out of the BADAC offices. Since that time, we have provided face-to-face support to hundreds of Brooklyn families. We conducted a needs assessment to learn more about the needs of our clients in Brooklyn which informed our next steps. We learned that there was a profound need for additional education and training in the community.

With the generous support of the Stavros Niarchos Foundation, we have been able to meet that need. The Foundation’s grant to the Chapter has enabled us to capitalize on existing relationships and form new ones in order to bring our Understanding Dementia, Legal & Financial, and Medicaid Home Care seminars; Family Caregiver Workshops; and support groups to a variety of neighborhoods through collaborations with organizations including New York Memory Center, Heights & Hills, Benson Ridge Senior Services, Zicharon, and the Brooklyn Public Library.

We were also proud to have celebrated our sixth annual Brooklyn Walk to End Alzheimer's on September 21. Participation grows each and every year and attendees often express their appreciation for the support they receive from the Chapter in Brooklyn. We are constantly exploring ways to enhance our presence and will keep you up to date on our progress.

Our success in Brooklyn encouraged us to find a way to do something similar in Queens and the generous support of the Stavros Niarchos Foundation has enabled us to do so. In addition to funding the expansion of our efforts in Brooklyn, the Stavros Niarchos Foundation grant has provided the support for the development of a similar program in Queens.

Our first step was to identify partners, and we could not have found better organizations to work with than Queens Community House and New York Hospital Queens. Their support of the project informed our progress every step of the way. After formalizing our partnerships, we began a search for the right professional to spearhead our efforts on the ground. After discussing trends across our three locations, we decided to hire a Korean speaking social worker as our Care Consultant in Queens. This decision not only allows us to meet the unique needs of this growing population in Queens but also enhances the Chapter’s linguistic and cultural capacity. Being able to offer services in Korean complements our existing capacity of services in English, Spanish, Mandarin, Cantonese and Russian. We were fortunate to find Yungae Yook, who joined us this past July. Yungae has over 12 years experience working with older adults in Queens, first in a long-term care facility and then with Visiting Nurse Service of New York. During her first two months at the Chapter, Yungae worked closely with our Helpline and care consultation staff, who supported Yungae’s training and development. In September, Yungae transitioned to working in Queens where she splits her time among our partner sites in Bayside, Fresh Meadows, and Kew Gardens.

As in Brooklyn, we are conducting a needs assessment to help us codify the plan to bring more programs and services, in more languages, to Queens.

On September 28 of this year, we celebrated our fourth annual Queens Walk to End Alzheimer’s. We are already hearing how beneficial it is for the community to have the access to our services locally, and we look forward to sharing more about our expansion efforts in future newsletter articles.

For more information about our programs and services in Brooklyn and Queens, you can contact Lorna and Yungae directly.

Lorna Walcott-Brown 718-287-1124 LBrown@alznyc.org

Yungae Yook 917-675-1445 YYook@alznyc.org

And you can always reach us through our 24-hour Helpline at 800-272-3900 or helpline@alznyc.org.
Support Groups

A Common Bond

“

At each group meeting, I learn I’m not alone and expressing my feelings in the group has practical results,” said Betsy Dean, a member of one of the Chapter’s support groups for spouses.

Betsy is the primary caregiver for her husband Charles, who is 90 and has been struggling with normal pressure hydrocephalus (NPH) for 15 years. NPH has three defining characteristics: dementia, gait and mobility problems, and incontinence.

Several years into his illness, Charles had two falls, which convinced Betsy she needed a support group. Until those falls, Betsy felt in control of her feelings and Charles’ care. Fortunately there was a group near Betsy’s home that she joined. Betsy and Charles have been living and working on the Upper West Side of Manhattan since 1966 and raising their five children. Betsy owned a store called Betsy’s Tree, a women’s clothing shop, which evolved into the well known craft cooperative Show of Hands and Charles built an economic consulting firm with clients ranging from governmental agencies to private businesses and nonprofit organizations. At 60, he retired and became a chef.

In the 1990’s, he and Betsy helped start a community AIDS program at St. Paul’s Episcopal Church on Ninth Avenue where Charles was the chef and Betsy ran the dining room.

At a recent meeting of Betsy’s spouses support group, a member shared that the night before her husband, who was in hospice care, told her he was ready to die. This group member expressed how they said goodbye to each other, her feelings about their conversation, and other end of life issues.

The timing of this group member’s experience was very helpful, because a few days after the group Betsy had a similar conversation with Charles, who asked her if she ever thought he would live this long and told her he was ready to die.

“I thought of our conversation in the group and I was able to use what we had spoken about and be supportive of Charles in the way I wanted to be,” Betsy said.

This is the ultimate benefit of being in a support group: your experience is shared by others and you know you are not alone.
2014 National Night Out Against Crime

The 31st anniversary of National Night Out Against Crime was another successful collaboration between community partners, civilians and the New York City Police Department on August 5, 2014. The Alzheimer’s Association, NYC Chapter staff members and volunteers represented the Chapter’s MedicAlert® Foundation + Alzheimer’s Association Safe Return® Program (MASR) throughout the five boroughs.

It was wonderful to see children and adults enjoying the food, inflatable bounce ride games, music and informational tables. We particularly enjoy this evening because it allows us to meet with the people in the community and answer questions concerning people with dementia who wander.

It is not unusual for someone diagnosed with Alzheimer’s disease or dementia to wander and become lost. In fact six out of ten people with dementia will wander at some point during the course of the disease. This can be extremely dangerous and even life threatening. Whenever a wandering incident occurs, it is stressful for the caregiver and the person with Alzheimer’s family members. This unpredictable behavior can happen at any time or place.

Every person who has been diagnosed with Alzheimer’s disease or a related dementia should enroll in the MedicAlert® Foundation + Alzheimer’s Association Safe Return® Program. MASR is a 24-hour nationwide emergency response service for individuals with Alzheimer’s or a related dementia who wander or have a medical emergency. We provide 24-hour assistance, 365 days a year, in 180 different languages.

Keep in mind that people with Alzheimer’s disease can have difficulty remembering where they live, their caregiver’s name or even their own name. When the New York City Police Department finds a lost person wearing an identifier (usually a bracelet), they call our MedicAlert emergency line and provide the emergency team with the lost person’s information. This critical information helps return the missing person to their family member or caregivers.

If you would like to enroll someone in this important program, you can call 646-744-2918 or visit our website at www.alz.org/nyc and click on the highlighted green area that says “Concerned About Wandering?” If you have any questions or concerns please feel free to contact us.
A Picture is Worth A Thousand Words…

Many of our Chapter’s programs have been greatly impacted by the expansion last year, and our Early Stage Services were certainly no exception. Since the opening of the Harry & Jeanette Weinberg Early Stage Center in April 2013, we have had the space and the opportunity to experiment with new programs for our clients with early-stage dementia. Some clients expressed a desire to volunteer for the Chapter, so we responded by developing a volunteering group. We offered Discover NY, a discussion group focused on little-known facts and trivia about our great city. We developed a chair yoga group called Mind & Body for individuals wanting to experience stretching, strengthening, breathing and relaxation exercises.

This spring, we found yet another creative way of engaging our clients with early memory loss. Four early-stage clients participated in A Thousand Words, a photography workshop. Over six weeks, they met as a group facilitated by professional photographers Annie Levy and Benjamin Heller. The clients decided on a theme, or a word, for each week and took photos that they felt represented that theme or word. What might you photograph to embody Beauty, Heart, or Sanctuary? Each participant had a unique perspective on the various themes. The core of the program was the experience of coming together each week to share and admire each other’s work. Naturally, personal connections were made as participants learned about one another’s backgrounds, personalities, and experiences through the discussions. Their illness came up in conversation, as that was the common thread among the group. However, having Alzheimer’s disease was not at all at the forefront of this experience. One participant’s feedback was, “I didn’t feel ill coming here. It was so nice to focus on something else.”

The workshop culminated in an evening exhibit, where the participants invited their families and friends to view their work. Favorite photographs were pre-selected by the group, printed and displayed at the event, and each group member had the opportunity to speak about what their images meant to them and how they related to the respective themes.

For some participants, this program meant reconnecting with a former hobby or passion. For others, it meant exploring a brand new way of expressing themselves through an art form. We hope for all, it was a chance to show the supportive people in their lives, and more importantly themselves, just how much they are still able to accomplish and contribute.

One might wonder, what makes the programs at the Harry & Jeanette Weinberg Early Stage Center unique? The truth is, many of our early-stage clients attempt to take workshops and classes at community centers or universities. Some do have a positive experience, but more often than not they are frustrated and defeated. They have difficulty “keeping up.” These programs are not designed for individuals with memory impairment. We offer similar enriching and interesting experiences to those found within community organizations, but we tailor them to meet the specific needs of our clientele. As we continue to expand our programming, we hope to offer other specialized programs like A Thousand Words in the future.

If you would like to learn more about the Harry & Jeanette Weinberg Early Stage Center, please call our 24-hour Helpline at 800-272-3900.

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

A collection of the clients’ work from A Thousand Words, now proudly displayed in the Harry & Jeanette Weinberg Early Stage Center’s Community Room

Annie Levy, the featured photographers, and Chapter staff at the June 26 exhibit
As part of our continued efforts to connect with the people and professionals in the community, the Alzheimer’s Association, New York City Chapter recently held a few successful events at local pharmacies in the Bronx and Queens.

On a sunny, midsummer day, we teamed up with At Home Solutions and Mt. Carmel Pharmacy in the Bronx for our first pharmacy outreach event. With a generous supply of purple awareness bracelets and pens displayed on our table in front of the store, we handed out over 200 bags filled with information about Alzheimer’s disease to customers and passersby. To increase awareness, we provided the staff with Walk to End Alzheimer’s T-shirts to wear, and the pharmacy promoted the event by posting flyers in the windows of a few local businesses and on area telephone poles.

Mt. Carmel Pharmacy has been in business for 50 years at the same location in the heart of the Belmont section of the Bronx, just a few blocks east of the famous Arthur Avenue. Brothers Roger, Armand and Michael Paganelli are third generation pharmacists and owners of the pharmacy. On any given day, the bustling business has a steady stream of customers — many of them regulars — coming in to pick up or drop off prescriptions while employees run in and out to make home deliveries. Due to a strong community presence and the Paganelli brothers’ commitment to their clientele, what began as a small family business catering to the needs of Italian immigrants continues to thrive as the neighborhood has become increasingly Hispanic.

Given the success of our outreach efforts, we held an additional outreach day in mid-September. It was a great opportunity for us to reconnect with the community. Some of the people we met that day remembered us from our first event, but admittedly had not approached us. They were happy for another opportunity, and, as is all too often the case, many regretted not knowing about our services sooner, but were grateful to finally have the information.

We expanded our local pharmacy outreach efforts with a day at City View Pharmacy in Astoria, Queens. Much like Belmont in the Bronx, the once very Greek neighborhood in Astoria has become increasingly diverse. Pharmacist Harry Xidias was on hand to help translate for his Greek clients, but our Spanish skills also came in handy. On a sunny, autumn day, joined by At Home Solutions and flanked by colorful balloons and a sidewalk sign announcing our event, we connected with over 200 people in the community.

Regardless of language or ethnicity, the words “Alzheimer’s” and “dementia” naturally elicit a negative response from people. No one wants to talk about these words, but they always seem to have questions. The Chapter’s Diversity and Professional Outreach programs allow us to connect and serve the variety of needs within a community. Pharmacists are part of the communities they serve; their clients depend upon them not only to distribute and dispense their medications, but for knowledge and accessibility. As the number of prescriptions for Alzheimer’s-related medications increases, so do the questions. Pharmacists can rely on the knowledge and services of the Alzheimer’s Association to support their clients and maintain their community commitment. In addition to outreach events such as these, a number of local pharmacies now provide a Prescription for Care pharmacy card that lists our Helpline number and enumerates our core programs and services with the Alzheimer’s prescriptions they fill.

For more information or to schedule an outreach day at your local pharmacy, please email GGallacher@alznyc.org or visit www.alznyc.org/mhp.
I is hard to believe that the end of 2014 is soon approaching. It has been an especially busy and productive year for us, as we continued to expand our programming and make advances in several of our specialized initiatives.

As you are aware, we are finishing the pilot phase of our 30-month palliative care program, which is bringing a model of comfort care to persons with late stage dementia who reside in nursing homes. Moving forward we will be developing both the internal capacity for integrating palliative care into all of our programs as well as working to identify the most effective and affordable ways of delivering information, support and training to the New York healthcare community so that they are able to provide palliative care to persons with late stage dementia.

This topic could not be more timely as we read daily about changes in the healthcare system and the many issues involved in providing good care.

We have worked hard this year to grow and diversify our funding base to have the financial resources to sustain and grow our programs. We rely on private support to make our work possible. Please take a moment to read our Year-End letter on the next page. I hope that you share in our pride for all that we have accomplished this year. Thank you.

With very best wishes for a happy and healthy New Year.

The Overhead Myth

The CEOs of Charity Navigator, GuideStar and BB recently published a letter titled The Overhead Myth (can be found in the Nonprofit quarterly (“www.nonprofitquarterly.org/philanthropy/22467-the-overhead-myth.html”). The objective of their letter is to correct the misconception about what matters when deciding which charity to support. It goes on to say that the percent of charitable expenses going to administrative and fundraising costs (“overhead”) is a misleading measure of a charity’s performance. In fact, these costs include important investments that charities must make in order to improve the quality of what they do as well as streamline their efforts to raise the funds needed to do it. Charity Navigator, GuideStar and the BB know that organizations that have built a robust infrastructure are more likely to succeed.

Our commitment to excellence can be seen in everything we do, from the programs we provide, to the events we run, to the investments we make in training, planning, evaluation and internal systems. While 73 cents of every dollar we spend goes to support the critically important programs we provide, the 27 cents ensures high performance and our ability pay for it. When you are making your charitable giving decisions, it’s important to know not only what your charity does, but how well they do it. The NYC Chapter takes great pride in the quality of what we do and how we do it, and we hope we make our clients, donors and supporters proud as well.

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@alznyc.org if you would like additional information.
Dear Friends of the New York City Chapter,

Known as the great equalizer, Alzheimer's makes no distinction based on race, ethnicity, gender, sexual orientation or income level. It is a disease that is present in every neighborhood of our city and equally devastating for all of the more than 500,000 New Yorkers affected. But, for those who make the call for help, the NYC Chapter is an unmatched lifeline for compassionate care and hope.

In 2014 we expanded our programs and broadened our reach so that all New Yorkers, regardless of where they live or work, have easier access to our free programs and services. Our new third floor Program Center is designed to accommodate the more than 15,000 clients we see each year, and ensure that they have ongoing access to all our programs and services through the difficult and long journey that is Alzheimer's. By opening satellite offices in Brooklyn and Queens, changing the culture of care in NYC nursing homes, and always embracing diversity, we have become one of New York City's most valued healthcare leaders.

Our success is also due to an extraordinary number of solid community partnerships. These relationships enable us to provide our clients with an unsurpassed level of access and expertise in dementia care, coupled with the ability to identify and quickly access the most appropriate resources for every family.

It is our pleasure to share with you some of our major accomplishments in 2014, all of which have moved us closer to our goal of providing free care and support for all New Yorkers who need us.

- We grew our lifesaving MedicAlert® + Alzheimer’s Association Safe Return® Program registry to over 21,000 New Yorkers.
- We offered 75% more Family Caregiver Workshops and eliminated waiting lists.
- We enriched our Early Stage programming with a specialized photography workshop and exhibition, and added a program of customized yoga and meditation for persons in the early stage.
- We completed our palliative care strategic plan, providing a roadmap for incorporating palliative care practices into our work and promoting these practices for persons with advanced dementia in a variety of settings throughout the city.
- We hired our first Korean-speaking Care Consultant for our newly established Queens satellite program.
- Nearly $14 million was awarded in Alzheimer’s Association grants to 88 scientific projects, including 78 awards through the International Research Grant Program.

2014 was a year of great expansion and growth for the Chapter. To sustain the pace and our ability to support the growing Alzheimer’s community, we have an ambitious Year-End Campaign goal of $500,000. Please help us meet our goal. Together, we can ensure that families throughout New York City have access to vital information, resources and support.

Best wishes for a peaceful and productive new year.

Sincerely,

Stephen P. Casper                                                    Benjamin J. Jenkins
Board Co-Chair                                                      Board Co-Chair

P.S. Gifts of appreciated securities may offer substantial tax advantages, and support the NYC Chapter. For more information, please consult your financial advisor.
The NYC Chapter is proud to introduce a new column that will bring our readers “up close and personal” to our Trustees. In the first of this series, we interview Emeritus Board member, Heath McLendon, who has served on the NYC Chapter Board since 2004.

LOU-ELLEN BARKAN (LEB): Heath, what brought you to the Alzheimer’s Association?

HEATH MCLENDON (HM): My mother developed Alzheimer’s in her 70s. It was heartbreaking. She was a very ladylike woman who would have been very embarrassed if she could have seen what was happening to her. After my father died, we contacted the Northern California Chapter of the Alzheimer’s Association and discussed residential care. But in the end, she went to live with her housekeeper, Maria, who took wonderful care of my mother until she died at 94. Later, a friend who was on the Board of the National Alzheimer’s Association introduced me to their Chair, who invited me onto the National Board. I spent six years on the National Board, where I focused on fundraising and planned giving before I joined the NYC Board.

LEB: And you’ve been with us for almost ten years, first as a Board member and now as Emeritus member. What are some things that have changed?

HM: When Social Security was established 85 years ago, life expectancy was 63 and you didn’t get Social Security until you were 65. You died before you got benefits and you never heard of Alzheimer’s. Today, life expectancy is 78 and you are likely to receive Social Security for 13 years, but also more likely to develop Alzheimer’s or a related dementia.

Ronald Reagan’s daughter, Maureen, was on the National Board with me. She was a positive force who worked both to define Alzheimer’s as a real disease and to raise awareness of the growing incidence. Today, the growing recognition of Alzheimer’s as a real issue has been most encouraging, as has the research trying to better understand it. We know people age differently, so finding out what causes Alzheimer’s is very challenging. While there are drugs that may slow the progression of Alzheimer’s, there is no cure or prevention, so in the meantime, we need to focus on care.

LB: Would you tell us something about your life?

HM: My father was a fireman in San Francisco, who became battalion chief. After Pearl Harbor, he oversaw civilian defense in San Francisco. I went to public schools, did reasonably well and I was offered a scholarship to Stanford. There I took all kinds of classes including Russian and ended up with a major in international relations. At our graduation, Dag Hammarskjöld, the UN Secretary General, was the commencement speaker. As the first graduate in international relations in many years, I got my picture in the newspaper.

Upon graduation I went directly into the army and, after officer training and Ranger School, to Korea for 18 months. Returning home I was accepted at the Harvard Business School where I earned my MBA. After my first year at Harvard, I got a summer job at the New York ad agency Benton & Bowles, where I met my wife. After I graduated, I went into a management program with Chevron, since I had worked for their gas stations during college. I liked working there, but I was more interested in Wall Street. And frankly, I had one completely inaccurate prediction: I couldn’t believe that we would not run out of oil in my lifetime.

I started work at Shearson, Hammill in 1960 at the best possible time. Nobody came to Wall Street during...
the Depression and World War II, and then Korea slowed things down in the 50s. In 1960 the daily volume on the stock exchange was three to four million shares, most sold in 100-share lots. You didn't have much of an institutional market or pension funds. Insurance companies invested in bonds. The Wall Street firms were private partnerships. The whole capital of Shearson, Hammill was 17 million. It was a completely different environment.

My first boss at Shearson was Murray Stefani, who had started the first equity research department. I watched as the business expanded very rapidly. Previously, recordkeeping was done by hand. Then Control Data developed a computer and Sandy Weill decided to set up a processing operation at Hayden Stone. In 1974, we sold Shearson, Hammill to Hayden Stone and I went to work for Sandy. Eventually, I became a Board member and was in charge of their institutional and research businesses. Every six or seven months, we did a merger and I lost my job to the guy on the other side. I never paid any attention; I just continued to work in a new position.

One year, Sandy suggested that I join the investment management business, which was just beginning to evolve. That took me out of the retail business, out of the research business and on to the asset management business. And that was a lucky break because of all the things I had done. I was better suited for that than anything else. We did merger after merger and evolved into Shearson Loeb Rhoades, Shearson American Express and Shearson Lehman Brothers. I stayed with the firm right through the time we eventually became Citigroup.

Over time, I had been chairman of 16 stock exchange-listed mutual funds, started the first fund to invest in Korea and the first fund to invest in the Italian stock market. We created innovative products and, as government oversight grew, we had to set up oversight between research and investment banking to avoid conflicts. That was my last assignment before I retired.

**LEB:** What a great story! And the issue of conflicts is not unique to Wall Street. Here we worry all the time about a perceived conflict between the priorities of providing resources for care and resources for a cure. How do you feel about the balance between care and cure?

**HM:** Care is something that you need today. Cure is something that you hope you can accomplish. The major focus has to be on the demands today. But you have to keep looking for a cure too.

**LEB:** In the absence of an effective therapy, the best therapy is good care, so these are not mutually exclusive and your support has made it possible for us to deliver good care to our clients. We’ve been so lucky to have you on our Board these many years to help us grow.

**HM:** My final comment would be how proud I am of the NYC Chapter. It’s an example of terrific management with an active and engaged Board. It’s very gratifying to be a part of this.
On Sunday, October 19, we closed out a record Walk season in New York City as more than 7,000 Walkers raised over $1,500,000 in Brooklyn, Queens and Manhattan and celebrated the 25th Anniversary of the Walk to End Alzheimer’s.

Thank you to our 2014 Walk Team Captains, Walkers, and their family and friends who supported our record breaking Walks.

Thank you to our staunch supporters, including our emcees, WABC-TV’s Bill Ritter and La Mega 97.9’s Reyna Franco and our celebrity champions David Hyde Pierce & Victor Garber. Congratulations to our honorees, Kenneth Shinozuka (Young Innovators Award), Ric & Jill Wolf/Foundation Cycling New York (Walk All Star Award), Mt. Carmel Pharmacy (Community Leadership Award), and our top fundraising team Ameriprise NY Metro led by their team captain Scott Hirsh.

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Photo Credit: Ronald L. Glassman & Amy Y. Lee
On Monday, July 28, the Chapter held the third annual A Round to Remember Golf Outing, sponsored by M Moser Associates, J.T. Magen & Company and WB Wood, at the Glen Head Country Club on Long Island. We could not have asked for a better day, with beautiful weather and 20 foursomes who joined us on the course. The event was a huge success, raising over $178,000, a Chapter record!

We could not have held this event without the help of our incredible Golf Committee. A special thanks to our Board member, Nathan Halegua, who started this event with us in 2011, and Committee Co-Chairs David Azus and Josh Halegua for all of their hard work. We would also like to thank all of our sponsors for their contributions to the event. We hope to see you in 2015!

Clockwise from top left: Ira Fishman, EVO Real Estate Group, Dr. Alan Schecter, Nassau Chest Hospital, Arnold Gamberg, EVO Real Estate Group, and Board member Nathan Halegua; Matthew Azus, Committee Co-Chair David Azus, Evan Azus, and Brandon Azus; David Azus and Nathan Halegua; Chapter CFO Steve Maggio, Chapter President & CEO Lou-Ellen Barkan, and Board Co-Chair Steve Casper; Aaron Halegua, Pearl Halegua, Nathan Halegua, and Josh Halegua; Steve Schwartz, Publicis Group, Laurie Hutner, WB WOOD, Richard Mines, WB WOOD and Mitchell Kunikoff, Lee & Assoc.
The Chapter’s palliative care work has been moving steadily forward, including some national recognition. In May, Jed Levine and I were invited to present at the annual state conference of the Alzheimer’s Association’s Wisconsin Chapter Network. It was a half-day, pre-conference intensive workshop with more than 300 attendees, who came to hear about our palliative care project.

In September, Jed Levine and I were invited by the Institute of Medicine, the health arm of the National Academy of Sciences, to present in Washington, DC, at the Expert Meeting on Advanced Dementia. In accordance with the National Plan to Address Alzheimer’s, the U.S. Department of Health & Human Services contracted with the Institute of Medicine to convene experts in the field of advanced dementia, and our presentation was part of a panel specifically addressing innovative practices in care for people with advanced dementia in various settings.

Finally, in October representatives from the nursing homes participating in our palliative care project (Cobble Hill Health Center, Isabella Geriatric Center and Jewish Home Lifecare, Manhattan), and I made a presentation about the project at the annual meeting of LeadingAge, in Nashville, Tennessee.

Locally, in September we presented on the palliative care project at a meeting of physicians who are members of the Metropolitan Area Geriatrics Society. We also sponsored an evening educational event on palliative care for consumers and professionals, as well as a training program for leaders of the Chapter’s support groups. Finally, we made a presentation about our work in palliative care at the 2014 State Society on Aging of New York’s Annual Conference in New York City in October.

We are in the final stage of collecting and analyzing the evaluative data for the project and will report on that in the next issue of the newsletter. First impressions are that trends are going in the right direction, reflecting progress and benefits for persons with dementia, their families and the staff who care for them.

In addition to our palliative care work, we are continuing to regularly produce our newsletters, ADvancing Care and Care ADvocate. ADvancing Care is intended for people who work in nursing homes, providing ideas and examples of best care practices. Care ADvocate also stresses good practices and is intended for the family members and friends of people with dementia residing in nursing homes. Both newsletters can be obtained for free by going to the Chapter website.

Ann Wyatt
Residential Care Policy & Strategy Consultant
AWyatt@alznyc.org

When I began my position as the Manager of Chinese Outreach at the Chapter six years ago, the number of staff was not as large, and we were all on the same floor. As the Chapter grew, due to the increasing demand for services, we expanded our space to two floors. The additional floor is a great space for the staff and volunteers to work and hold workshops, seminars and trainings. Now, there is more room for staff to meet with families to provide guidance and counsel in a private, confidential setting.

Services for the Chinese community have expanded as well. Currently, the Chapter has 14 brochures in Chinese, a Chinese information package, a quarterly Chinese newsletter, three Chinese-speaking support groups, training classes for Chinese home attendants, Chinese legal and financial workshops, an annual Chinese caregiver luncheon and a Chinese caregiver trip.

Asian enrollment in the MedicAlert® + Safe Return® Program has increased 54% in the last year. In November of 2011, due to the high demand for services from the Chinese community, the Chapter hired a Chinese-speaking Care Consultant, Serene Nie. The number of Chinese clients who contact our 24-hour Helpline for consultation, information and referrals has increased to more than 300. They greatly appreciate our support, many asking if we could provide more programs and activities for them. Recently, I spoke with caregivers regarding the trip to Fire Island. They are very happy that we can provide respite programs for them such as the trip and luncheon.

I believe the expansion to the third floor benefited the staff and volunteers, but most importantly the families we serve. It allowed us to provide more workshops, events and activities for persons with dementia, their families, and professionals. As a result, the quality of life for the person with dementia and the caregiver can be improved.

Chinese Outreach Update
Watching *King Lear* through the lens of an Alzheimer’s professional is a curious experience. From the very first scene when the aging monarch — the King of all Britain — decides to step down from the throne and divide his kingdom among his three daughters by testing their love for him, I knew something was very wrong. Who in their right mind would put their children in that situation?

The answer, of course, is no one. As I watched the performance earlier this summer in Central Park’s Delacorte Theater, I thought, the poor man is demented. And I braced myself for disaster.

Goneril, the eldest daughter, went first: “Sir, I do love you more than word can wield the matter ...”

It rang false. But, right answer, I thought.

Regan, up next, one-upped her sister, saying that Goneril “comes too short, I profess myself an enemy to all other joys....”

Good girl, I thought, play along with him. That’s what he needs to hear.

Lear, now very pleased, turns to his youngest and most beloved child and chides her, “A third more opulent than your sister? Speak.”

Cordelia, angered by the game and by her duplicitous, scheming sisters said, “Nothing, my lord... Nothing.”

My heart stopped. I wanted to stand up, right there in front of John Lithgow, Annette Bening and the entire magnificent cast and yell, “1-800-272-3900! Call the Alzheimer’s Association 24-hour Helpline. We can help you.”

What ailed King Lear has been the subject of scholarly debate for centuries. As far back as 1866, author A.O. Kellogg in his book *Shakespeare’s Delineations of Insanity, Imbecility and Suicide*, opined that Lear’s behavior could be attributed to senile dementia. H. Somerville, in *Madness and Shakespeare* (Richards Press: London, 1929), wrote that Lear showed “signs of mental deterioration due to old age.” And as recently as February, British actor Simon Russell Beale said that medical research he did in preparation to play Lear suggested that the monarch could have been suffering from Lewy Body dementia.

Regardless of a specific diagnosis, if my 10 years at the New York City Chapter of the Alzheimer’s Association has taught me anything, it’s that communication and planning are key to helping a family deal with dementia.

The problem, in Lear’s case, is not that he is asking the wrong question — because there is no right or wrong question for a person with dementia. It’s that Cordelia is not able or willing to see the question for what it is: the product of her father’s demented mind.

Before Act 1, Scene 1, is over, with Cordelia now disinherited by a furious Lear, even the evil sisters recognize that their father is no longer their father.

Goneril says, “You see how full of changes his age is... He always loved our sister most, and with what poor judgment he hath now cast her off appears too grossly.”

Regan responds, “Tis the infirmity of his age, yet he hath ever but slenderly known himself.”

In professing their love as they did, Goneril and Regan were far more effective in controlling the situation than Cordelia, their underlying motivations notwithstanding.

As in any great Shakespearean tragedy, the consequences of Cordelia’s words and Lear’s reaction are devastating. At the end, the family members are all dead and the kingdom lies in ruin. And while today, such a dysfunctional family dynamic would not end in a tragedy of such global proportions, Alzheimer’s can have an equally devastating impact on the personal lives of family members.
King Lear has many valuable lessons for family caregivers. Let’s start with communication. One of the fundamental lessons that families must learn is: don’t fight the reality of the person who is living with Alzheimer’s — even though their words can be hurtful.

Without warning, one day, my mother who was in the late stages of dementia, looked at me angrily and demanded to know who I was. I was stunned by her harsh tone.

“I’m your daughter,” I replied.

Her voice was cold. “Impossible.”

“Who do you think I am?”

“I have no idea.” She raised her voice. “Where is my daughter?”

I could have yelled and said, “What do you mean? Who am I? I have been your daughter for more than six decades. I have been breaking my back taking care of you for years.” But I didn’t. Social workers had taught me not to argue. So I calmly said, “Your daughter is close by. You’ll see her soon.”

The lesson here, as it should have been for Cordelia is: put yourself in the mind of the other individual, however hurtful or crazy they may seem. Part of your job as a caregiver is to create moments of peace when there is agitation.

A second key lesson is: you must be prepared. Every day, I hear stories about children fighting over what dad would want. Who’s in charge of his care? What do we do with his finances? Do we take extraordinary measures at the end to extend his life? How are his assets to be divided?

At the beginning of every family’s Alzheimer’s journey there should be a planning process. Key legal documents must be in place.

Oh, if King Lear only had a durable power of attorney authorizing someone he trusted to make legal and financial decisions. Also critical is a health care proxy giving one person legal authority to make important medical decisions. A living will is a good supplement to the proxy. Signed while the person is still of sound mind, it allows a person with dementia to clearly communicate wishes regarding end of life care. And finally, a will can help you divide the kingdom without bloodshed.

With help and information from the Alzheimer’s Association, communicating with someone who has dementia and planning for the inevitable end can be a smoother process — and one that avoids tragedy of Shakespearean proportions.

Originally published on huffingtonpost.com
As a team, Athletes to End Alzheimer’s works tirelessly throughout the year to raise awareness and crucial dollars to help support the mission of the Alzheimer’s Association, New York City Chapter. Whether the athletes are sending out emails to friends and family asking for support, running in parks across the country in their purple Alzheimer’s Association gear to raise awareness or just posting to Facebook about the latest news in Alzheimer’s research and care initiatives, their goals are always the same: to educate people about their personal Alzheimer’s stories. And as they publicly share their commitment to the cause, they reiterate that, as the number of people affected by Alzheimer’s continues to grow, the Alzheimer’s story needs to be EVERYONE’S story.

During the summer, the answer to how they plan to end Alzheimer’s is simple: They TRI. And by that, we mean they swim, bike and run as participants in the New York City Triathlon and the Ironman North American Championship in Mont Tremblant. For most people, the summer is usually a time for rest, vacation and lazy days. For our participants, summer is the time to push physical boundaries and become three-sport athletes. They start to train in the early spring with morning runs, evening swims and long weekend bike rides to build up their strength and their stamina for the upcoming summer races.

In August, 15 athletes took to the water, roads and parks in support of the Alzheimer’s Association. For over half the team, this was their first long distance race. But for them, the distance was just a portion of the miles that they were willing to complete in honor and memory of their loved ones who are bravely living with or who had lost their lives to Alzheimer’s disease or other dementias. Together they raised almost $50,000 in support of programs, services and research. And all their efforts started with the initial question: What can I do to help end Alzheimer’s?

The answer was simple for them and can be for anyone else who wants to get involved. Decide to be active. Whether you are a novice athlete or the fastest person on your street, the Athletes to End Alzheimer’s program has a space and a race that can accommodate you. Our team members may start out describing themselves as individuals: a nurse, a banker, a student, a lawyer. But at the end of all our events, their identity is united: They are caregivers. They are advocates. They are athletes. They are the future. They are on a mission to end Alzheimer’s.

Visit www.alznyc.org/athletes or call 646-744-2966 to get involved today!
On Monday, August 25, 2014, Nathan Halegua, a member of the NYC Chapter’s Board of Directors, was joined by his family and close friends to celebrate the dedication of The Oro and Joseph Halegua Care Consultation Room. The Care Consultation Room offers clients a private space where they can meet with a care consultant for an in-depth and personalized consultation. During a care consultation the goal is for each family to develop a better understanding of the disease, make a plan to secure needed care, and develop strategies for the best possible symptom management and communication.

UNDERSTANDING DEMENTIA

What you need to know and where to go.

All meetings are free of charge and offered in Manhattan, Queens, Brooklyn and the Bronx.

Please call our 24-hour Helpline at 800-272-3900 to register for meetings.
Research on Alzheimer’s disease prevention and prevalence took center stage at the Alzheimer’s Association International Conference® (AAIC®), held July 12-17, 2014, in Copenhagen, Denmark. The world’s largest gathering of Alzheimer’s and dementia professionals, AAIC drew more than 4,300 researchers, physicians, and other healthcare professionals from 75 countries. Participants had hundreds of sessions from which to choose over the five-day conference, including 425 oral sessions and more than 1,600 poster sessions, plus a full day of pre-conference sessions. This 26th annual AAIC was opened by Her Royal Highness Princess Benedikte of Denmark. “Nobody knows better than this audience the impact of the illness on the individual affected and their family,” said the Princess. “How encouraging it is that we have thousands of brilliant minds advancing Alzheimer’s and dementia research around the world. It is because of this work and the partnership with the Alzheimer’s Association that the international research community will defeat Alzheimer’s.”

Results from four research studies reported as “developing topics” at the Alzheimer’s Association International Conference 2014 in Copenhagen included significant advances in evidence regarding treatment and early detection of Alzheimer’s disease and dementia, as well as new ideas in the basic brain science of dementia that may lead to new diagnostic and treatment targets.

Developing topics at AAIC are authorized late submissions to the conference and often include last-minute calculations and data analyses. More than 150 developing topics abstracts were accepted this year out of the 2,431 total scientific presentations at AAIC 2014. The following are four particularly noteworthy submissions:

• A two-year clinical trial in Finland of a multi-component lifestyle intervention in 1,260 older adults at risk for cognitive impairment and Alzheimer’s showed that physical activity, nutritional guidance, cognitive training, social activities and management of heart health risk factors improved cognitive performance, both overall and in separate measures of executive function, such as planning abilities and the relationship between cognitive functions and physical movement.

• A randomized trial in the U.K. involving family caregivers of people with dementia tested a short psychological support program delivered by graduate students. The intervention significantly reduced caregivers’ anxiety and depression, and this impact lasted for two years. At AAIC 2014, the scientists also will report on the impact of the program on costs of care.

• In a post-mortem study of more than 340 brains of people identified after death as having Alzheimer’s disease-related changes, researchers identified that a third abnormal protein, known as TDP-43, may play an important role in Alzheimer’s along with well-known beta-amyloid and tau proteins. People with TDP-43 were 10 times more likely to have been cognitively impaired at death than those without it.

• A study in which cognitively normal seniors were measured for brain tau protein levels using positron emission tomography (PET) scans showed that memory decline was linked with higher levels of tau buildup in several brain regions, demonstrating the potential value of these scans in early detection of dementia and in identifying participants for research studies.

For more information and to get involved, visit www.alz.org.

Article Credit: Alzheimer’s Association International Conference
Awareness, Allocation & An Affair to Remember

By Marielle Mindlin Bernstein, Junior Committee President

What is the one thing you never want to forget? Inspired by the YouTube video “One Thing” that Andy Scherr of the Massachusetts/NH Chapter created, the JC is asking people to share the one thing they never want to forget. The devastating truth is that of those who are asked this question, a portion will one day forget that one thing. Asking people to think about the most cherished thing to them personalizes how shattering the effects of Alzheimer’s truly is.

Our collection of “One Things” is continuously growing and can be viewed at alznycjc.tumblr.com. The diversity of answers reflects how Alzheimer’s affects everyone and their families in such different, yet devastating ways. So what is the one thing you never want to forget? Is it your family? Your name? Your identity? Share your answer today and help us spread awareness of Alzheimer’s disease.

In addition to spreading awareness, the Junior Committee has been very busy this last year raising funds for the NYC Chapter. The JC considers it an honor and a privilege to be able to allocate which programs and services our donations fund, and therefore our allocation meetings are always very exciting. In August the JC met to allocate the funds raised from our 2013 Masked ‘Til Midnight Gala, 2014 Ride to Remember, 2014 Athlete to End Alzheimer’s events, personal fundraising campaigns, and general donations.

The allocation meeting consisted of Jed Levine and other Chapter staff presenting proposals for programs and services that the JC could donate their funds toward. After the informative presentations and a lively discussion, the JC voted to allocate $25,000 for the Special Assistance Fund, $10,000 for Chinese Outreach, and $4,200 to fund the TrackVia system for the 24-hour Helpline for an entire year, all of which allows the Chapter to better serve the NYC population. The Junior Committee has worked very hard this past year to raise this money, and we know that the NYC Chapter will use these funds to provide the best service to anyone and everyone who needs our help.

Until there is a cure, the Junior Committee will continue to work to raise awareness and funds for research, programs, and services. And that is why on September 19th, the Junior Committee held our signature fundraiser, our annual gala. This year the gala took on a 1920s theme and was called Speakeasy Soiree. The historic Harold Pratt House on the Upper East Side was glowing with 1920s swagger. The bar was stocked with our sponsors Remy Martin (Platinum Sponsor), Brooklyn Brewery, Don Julio, Captain Morgan, and Bootlegger Vodka. Dessert was provided by the delicious Insomnia Cookies, and our numerous silent auction items were a hit. The various rooms of the mansion were decorated with donated honorary floral arrangements. We raised over $60,000!

The JC would like to extend a special thank you to all who made this event possible, including but not limited to, the event chair Liz Johnson, the entire gala steering committee, and all the help from the Chapter staff. We look forward to having you all join us next year!
**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:**
- November 6 12:30 – 2:30 p.m. Queens
- November 11 5:30 – 7:30 p.m. Manhattan
- November 14 Noon – 2:00 p.m. Manhattan
- November 19 5:30 – 7:30 p.m. Manhattan
- November 19 6:00 – 8:00 p.m. Brooklyn
- December 4 12:30 – 2:30 p.m. Queens
- December 9 5:30 – 7:30 p.m. Manhattan
- December 10 1:00 – 3:00 p.m. Brooklyn
- December 10 5:30 – 7:30 p.m. Manhattan
- December 12 Noon – 2:00 p.m. Manhattan
- January 8 12:30 – 2:30 p.m. Queens
- January 9 Noon – 2:00 p.m. Manhattan
- January 13 5:30 – 7:30 p.m. Manhattan
- January 21 5:30 – 7:30 p.m. Manhattan
- January 21 6:00 – 8:00 p.m. Brooklyn

**Upcoming Dates Just for Professionals:**
- December 10 3:00 – 5:00 p.m. Manhattan

**Upcoming Dates in Chinese:**
- November 15 10:00 – Noon Manhattan
- December 20 10:00 – Noon Queens

**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:**
- November 3 Noon – 1:30 p.m. Manhattan
- November 17 5:30 – 7:00 p.m. Manhattan
- December 1 Noon – 1:30 p.m. Manhattan
- December 15 5:30 – 7:00 p.m. Manhattan
- January 5 Noon – 1:30 p.m. Manhattan
- January 22 5:30 – 7:00 p.m. Manhattan

**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:**
- December 6 & 13 10:00 a.m. – 3:00 p.m. Manhattan
- January 6, 13, 20 & 27 Noon – 2:30 p.m. Manhattan
- January 7, 14, 21 & 28 5:30 – 8:00 p.m. Manhattan

Attendance is required at all workshops in a series.
Monthly Education Meetings

Topics for each meeting vary on a monthly basis. Recent topics include Activities for People with Dementia, Challenging Behaviors and Early Stage Issues.

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

**November 10 (Manhattan)**
- **Topic:** Late Stage Alzheimer’s: Providing Comfort and Care
- **Speaker:** Alejandro Berti, Dementia Care Trainer, Alzheimer’s Association, NYC Chapter

**December 8 (Manhattan)**
- **Topic:** Ego to Essence: The Spirituality of Family Caregiving
- **Speaker:** Reverend Greg Johnson, Creator/Director, EmblemHealth’s Care for The Family Caregiver Initiative

**January 12 (Manhattan)**
- **Topic:** Dementia & Technology
- **Speakers:**
  - David V. Pomeranz, COO, Hebrew Home at Riverdale, Balance smartphone app;
  - Jenny Rozbruch, Founder, CEO & Designer of GreyMatters;
  - Lauren Volkmer, Dementia Care Trainer, DementiaAides.org, Alzheimer’s Association, NYC Chapter

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

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**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:**

- November 20 3:00 – 4:30 p.m. Brooklyn
- November 25 5:30 – 7:00 p.m. Manhattan
- December 16 5:30 – 7:00 p.m. Manhattan
- January 13 5:30 – 7:00 p.m. Manhattan

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**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:**

- November 6 5:30 – 7:00 p.m. Manhattan
- December 4 5:30 – 7:00 p.m. Manhattan
- January 8 5:30 – 7:00 p.m. Manhattan

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**Upcoming Events**

**NOV 13**

Mind & Body
Come to our NEW group called “Mind and Body for Caregivers” in Manhattan. The group 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.

**DEC 11**

Mind & Body
“Mind and Body for Caregivers” in Manhattan. The group 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.

**JAN 8**

Mind & Body
“Mind and Body for Caregivers” in Manhattan. The group 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.
The poetic plaques adorned with loving words of family, caregivers, and friends enhance the beauty of Bryant Park. Their personalized messages create a special place in the park for supporters and visitors alike.

For more information please contact Crissy Vicendese at cvicendese@alznyc.org or 646-744-2927.