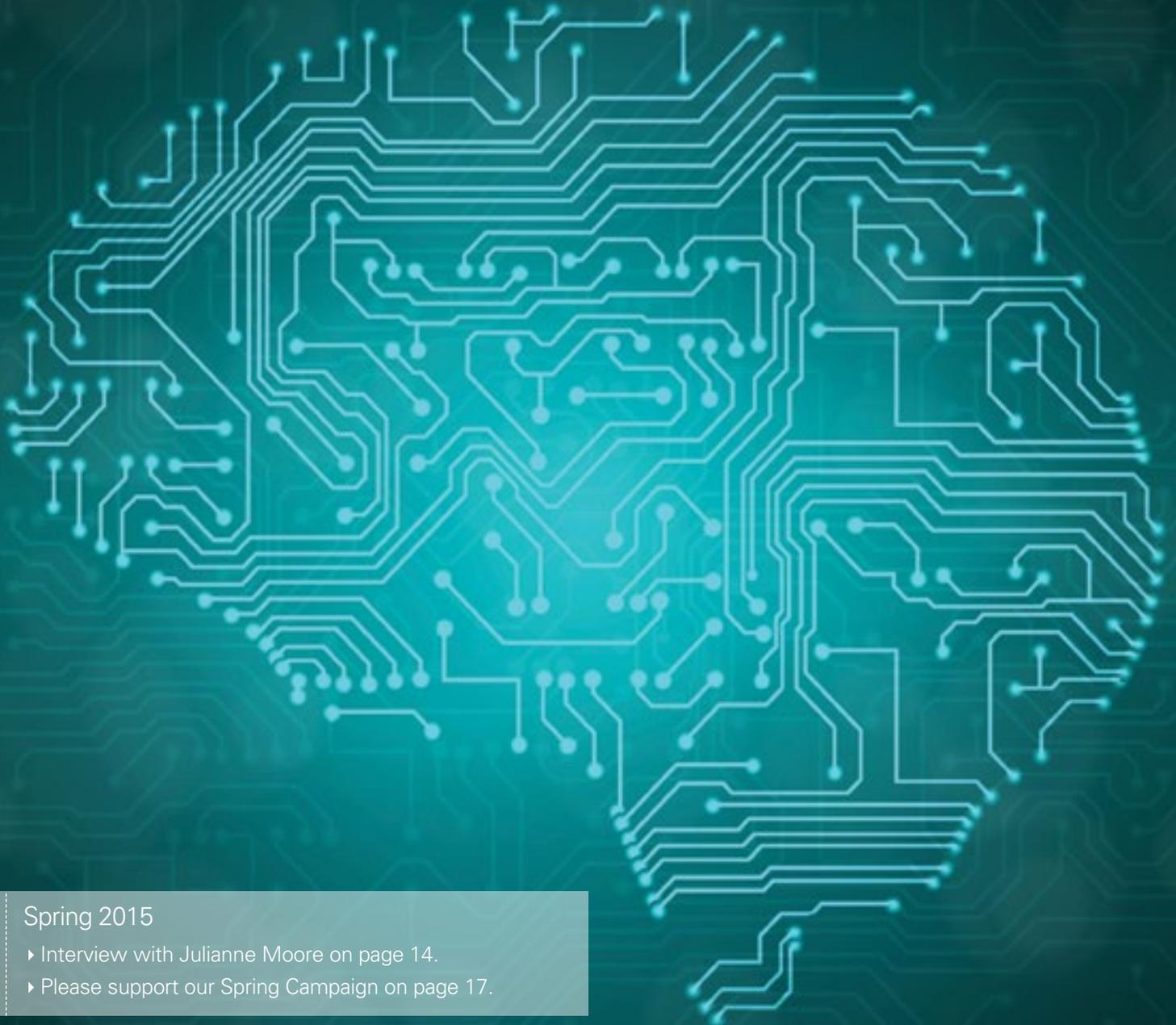


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New York City Chapter

BRAVE NEW WORLD

Dementia Care in the 21st Century



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Spring 2015

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New York City Chapter

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Dear Friends,

Technology has revolutionized the way I live and work. I love this brave new world and welcome it into both my personal and professional life. Innovations like Fitbit, Netflix, and Facebook keep me healthy, entertained, and connected with friends from long ago. And with 24/7 internet availability and advances in telecommunications technology, the New York City Chapter of the Alzheimer's Association is always at my fingertips.



Lou-Ellen Barkan
President & CEO
LBarkan@alzny.org

I can work almost anytime, anywhere. My productivity and efficiency have skyrocketed.

But, sometimes there's a cost. Romantic getaways with my husband have been interrupted by emergency work calls. On special afternoons out with my granddaughter, I can almost feel my blood pressure rise with the incessant vibration of my iPhone. A quiet Sunday night at home enjoying *The Good Wife* often ends when I become too engrossed in work emails and miss the point of the plot.

I urge all Alzheimer's caregivers, as well as their friends and family, to fully embrace technology and take advantage of the many benefits and improvements it can bring into your lives. But a word of caution: don't let it take over your life and become a substitute for the things that really matter.

The tools available today to caregivers can be life-altering. For instance, the NYC Chapter's website is an excellent resource for caregivers who need helpful information, classes, workshops, and support groups.

Together We Care™ (formerly dementiaaides.org) — another of our great innovations — connects home health aides who have completed the NYC Chapter's Dementia Care Training for Professional Caregivers and

families seeking to hire trained aides to provide care.

The Balance app for Alzheimer's caregivers helps you track medications, keep tabs on doctor appointments, and monitor the health and behavior of your family member and immediately share the information with other caregivers and health care professionals.

Caregivers can take advantage of automatic bill paying to make sure that mom's bills are paid on time and that heat and electricity remain on during the dead of winter.

And through email, phone calls, and social media, friends can easily stay in touch with family caregivers who often sacrifice their personal lives and well-being while caring for a person with Alzheimer's.

Technology can greatly ease a caregiver's burden. Instructional videos on YouTube provide education, state-of-the-art equipment allows you to watch your loved one from next door or halfway across the country, iPods provide a click-and-go tailored library of favorite music that can make someone with dementia come alive, and GPS technology tracks a wanderer's whereabouts — to name a few.

But let's not become so engaged with technology that we forget that 21st century innovation is no substitute for hands-on, loving care

and affection for both the person with dementia and the caregiver. Watching a person with dementia on a video monitor is no substitute for loving physical touch. Playing music on an iPod cannot replace patiently listening and paying attention even when the person with dementia may not be making any sense. Going to the Alzheimer's Association website and researching support groups is meaningless unless you actually get up and join one. Using a GPS tracking device to monitor your dad's whereabouts is no replacement for taking him on a leisurely stroll, hand-in-hand, around the block. A friend's email to a caregiver is not the same as a personal visit and a warm hug. A telephone call is not the same as a shoulder to cry on.

Albert Einstein once said, "It has become appallingly obvious that our technology has exceeded our humanity."

With some common sense, compassion, and patience, I know the Alzheimer's community can prove Mr. Einstein wrong.

P.S. Please support our Spring Campaign and honor someone you love for Mother's or Father's Day on page 17.

Dear Readers,

I'm a new iPhone devotee, but I've had an iPad by my side since Apple introduced the first version. It has helped me keep track of apps and devices to serve our community. Recently, I was captivated by PARO, a soft animatronic robotic seal produced in Japan which is used to comfort those with dementia. Adorable, lifelike PARO purrs and cuddles. To be honest, I didn't want to give it back.

I'm also a fan of Music & MemorySM, a program that uses the simple technology of iPods to bring individualized playlists to persons with dementia. Google *Alive Inside* or visit MusicandMemory.org to see how previously unresponsive people with dementia react to familiar and favorite music.

With the explosion of innovation over the past two decades, we have revolutionized our ability to communicate, to gather information, and to explore resources. Many new programs and devices have the capacity to assist, monitor, and comfort those affected by Alzheimer's and their caregivers. However, we all have concerns about the effect of technology on our social and family relationships.

Much has been written about the negative effects of social media and the overuse of email and texting, which lack the traditional social cues that prevent misunderstandings, sometimes with unfortunate consequences. Is all this communication forcing us to give up our traditional social skills? Are we losing the ability to look each other in the eye and talk, to daydream, to spend time alone without being connected to a screen? Can we still hold meaningful, reasoned conversations? And what about the effects on the cognitively impaired? Are they more at risk of becoming victims of online scams and easy prey to financial predators? Is the time caregivers spend online taking them away from the physical and human interaction that really provides comfort?

We believe this bears watching. Alzheimer's and other dementias profoundly affect an individual's ability to think, to communicate, and to function independently. The disease affects memory, self-awareness, insight, planning, and the use of language. Yet it is these very functions that make us profoundly human, and through which learning, healing, and growth occur. Yes, there is an important role for information gathered through an internet search and much to be gained from online communication and training. But, the comfort and connection that takes place between human beings in a classroom, on a New York City Chapter Helpline call, or in a support group cannot be replaced by a computer program.

In the face of today's rapid technological changes, we are proud of the Chapter's commitment to invest in alternative ways for family members and persons with the disease to access our resources. Our 24-hour Helpline is one example of high-tech/low-tech access. We believe that there is no substitute for a personal conversation with a caring, concerned, knowledgeable professional who provides comfort and reinforces our message that you are not alone. But to ensure that everyone can reach us in a way that works best for them, we also invest in our website, our email services, and hiring and training a staff of social workers available for face-to-face meetings.

The National Alzheimer's Association also has a wide range of online training for professionals and



Jed A. Levine
Executive Vice President,
Director of Programs & Services
JLevine@alzny.org

family members. AlzConnected[®] is an active online community for people with the disease and family caregivers. TrialMatch[®] expedites the connection between a potential research subject and an appropriate clinical trial. Web-based advocacy resources make it easy to send messages of support and concern to elected officials. These resources are invaluable, yet in our experience, the many thousands of New Yorkers who visit the Chapter are seeking that irreplaceable human connection in our support groups, Family Caregiver Workshops, education meetings, and on our 24-hour Helpline.

As with most everything, we know the importance of balance — to preserve the resources that facilitate personal communication, while also building and supporting technology that can help our community. And as the world of technology becomes more sophisticated, we are committed to changing and growing with the times.

However you choose to reach us, be assured that we are here for you 24 hours a day by phone, by email, or through our website at www.alz.org/nyc. Don't wait to get in touch. You will be glad you did!



On the heels of a very successful 2014, the Chapter is moving full steam ahead with an exciting array of events, fundraising initiatives, educational programs, and outreach efforts. Members of the Chapter also continue to be an active presence in the media – with appearances in print, on television, and online – and are often called upon for their expertise and guidance on issues related to Alzheimer’s and dementia.

In an extraordinary piece of journalism, *The New York Times* reporter Mireya Navarro wrote an eye-opening story about the problem of wandering among New York City’s Alzheimer’s community. The Chapter was proud to work with the reporter on this beautifully illustrated story, “A Warning to Prepare for a Grayer City,” which featured the personal accounts of caregivers and their struggles caring for someone who wanders. Filled with alarming statistics, the story included the important perspectives of our own Executive Vice President, Director of Programs & Services Jed Levine and Lieutenant Christopher Zimmerman, Commanding Officer of the NYPD Missing Persons Squad. We urge you to read the story and to sign up for the Chapter’s MedicAlert® + Alzheimer’s Association Safe Return® Program if you need help.

This past December, Chapter President and CEO, Lou-Ellen Barkan, was featured on *The Huffington Post*. Her blog, “Resolutions for Dementia Caregivers,” provided thoughtful and practical guidelines for the caregiver to ensure their own well-being in the New Year. Her tips covered a wide range of issues including how to ask for help, the importance of getting your financial and personal affairs in order, and why it’s OK to lean on others for assistance with meals, supervision, and household concerns. Lou-Ellen also stressed how vital a resource the Chapter’s website (www.alz.org/nyc) is for support and all things related to the disease. Help is only a phone call or click away! The post also garnered much traction on social media with 2,200 “Likes,” 505 “Shares,” and almost 80 “Retweets” — further exemplifying the impact modern technology has on reaching greater audiences and making them aware of all the Chapter has to offer.

Also featured on *The Huffington Post* — just in time for Valentine’s Day — was Lou-Ellen’s blog, “Love in Time of Alzheimer’s.” This reflective and emotional post detailed how love can survive dementia, in addition to growing in new ways. It stressed accepting your loved one for all that they are and provided words of encouragement for caregivers to live by.



From left to right: Keith Kelly, Matthew Thomas, Lou-Ellen Barkan, Ed Kelly, Mike Kelly at the 11th Annual Kelly Gang fundraiser on St. Patrick’s Day. Proceeds from the event benefitted the Alzheimer’s Association, NYC Chapter. Thank you to all of the Kellys! (Photo courtesy of the Kelly Gang, photographer Rohanna Mertens)

Also in December, Jed Levine was featured on Staten Island Community Television. Jed discussed Alzheimer’s disease and dementia and the many free services offered at the Chapter, including early stage services, care consultation, the 24-hour Helpline, and MASR. He also spoke about how the community can get involved in the fight against Alzheimer’s disease. This hour-long segment provided helpful information and tips for community members and, after the segment aired, the Chapter saw a 44% increase in Helpline calls from Staten Island residents.

In January, Latino Outreach Manager, Roberto Reyes, was a guest on “Tiempo,” a weekly round-table discussion show featuring topics affecting and relating to Hispanic citizens on WABC-TV, Channel 7. Roberto spoke about the Chapter’s Latino outreach, the rise in the number of Latinos with Alzheimer’s, and the stigma surrounding Alzheimer’s in the Latino community. He was joined by caregiver Alba Sánchez, who discussed her experience with the disease and caring for her mother. This segment drew in 80,000 viewers, helped the Chapter establish another point of connection within the Latino community, and provided details about how those interested could contact the Chapter and utilize their resources.

Our Brave New World

By Jamie Talan

For Victor Wang, it was the thought of his grandmother living alone in Taiwan. She was lonely and depressed, and life became more complicated after she was diagnosed with Lewy Body dementia. A few years ago, Victor started a company offering a virtual companion, an avatar, manned around-the-clock by a team of remote caregivers offering comfort, direction, protection, and a familiar voice.

Sha Yao lost her grandmother to Alzheimer's before she got the chance to show off a set of dementia-friendly tableware she developed. Volunteering in three adult day programs, she saw cognitively impaired people grapple with plates and cups, ending up with dessert on their laps. She learned what it would take for people to eat with dignity and created Eatwell, colorful and clever tableware that builds on more than 20 innovative elements specifically for cognitively and physically challenged people.

These are just two of the people who have taken up the challenge of creating innovative tools to make life easier and safer for people with dementia. Advances in technology allow people with dementia to communicate with family members who don't live nearby, to improve communication by engaging with talking avatars, and to use apps that remind them when to take their medications and what to take.

Caregivers use apps to track sleeping habits, share medical updates with relatives, and place sensors on objects such as pill bottles and stoves that will alert them if a bottle hasn't been opened in a day or if the stove has been left on. There are tools that help people in the early to moderate stages of Alzheimer's to remember and stay focused on their daily tasks. There are also apps that monitor bank accounts to alert users of frauds, scams, or even expansive spending that may have resulted

from contact with people preying on those with cognitive impairment.

Katy Fike, Ph.D., is co-founder of Aging2.0, a global innovation network. Aging2.0's mission is to accelerate innovation focused on improving the lives of older adults. In addition to hosting events held all over the world, Aging2.0 has collaborated with the Stanford Center on Longevity to run a student design challenge focused on the needs of older adults. Last year's challenge focused on solutions for people with cognitive impairment, and Sha Yao's Eatwell dining set won the competition.

Eatwell: Sha Yao has lived in San Francisco since 2008 and has an MFA from the Academy of Art University, where she developed Eatwell during her senior year. "I was very close to my grandmother and I felt so helpless watching her struggle to eat. I tried to learn more about the condition and understand ways that could help, and I found research about the use of color and its ability to get people with Alzheimer's to eat more." A Boston University study on color found that people who ate from red or blue plates and cups ate 24% more food and drank 84% more liquids. Yao identified the eating challenges of people in adult day care centers and addressed each problem from a design perspective.

All of her tableware is lined with high contrast colors to reduce confusion; the inside of each piece of tableware has colors designed to be easier to distinguish the tableware from items of food. The bowls are slanted on the bottom and the spoons match the natural curvature of the bowls, so people can better scoop up their food. The cups are designed with anti-slip bottoms and lids to prevent spills. The handles are built for fingers and hands with arthritis.

"It has been an amazing journey. I just wanted to help my grandmother," said Yao. Her grandmother passed

away in 2010, but her spirit lives on in her granddaughter's designs. For more information, visit: www.eatwellset.com.

Gerijoy: As a child, Victor Wang would have loved to have a video camera hook-up for his grandmother, whose loneliness, depression, and ultimately, dementia forced his mother to relocate to Taiwan for a year when he was only eleven. He studied engineering in college and during a master's program at the Massachusetts Institute of Technology, Victor was involved in human-machine interactions for NASA's telerobotics program.

For people with mild to moderate dementia, Wang and his colleagues created friendly looking animal avatars whose facial expressions mimic what they are saying. The avatar is manned by remote human caregivers throughout the day to provide care and companionship. A video camera focuses on the person with Alzheimer's or on the room to allow for one-on-one communication and coaching. During these interactions, the avatar's eyes are open to indicate that remote caregivers can see and hear what the user is doing or saying. Remote caregivers go online every 15 to 20 minutes to check on the user, and spend about an hour a day in in-depth conversation. The patient's privacy is always respected. When the patient is engaged in personal care, the avatar goes to sleep.

When the avatar is awake and interacting with the user, the remote caregivers document each communication and keep observations in a journal. Families have access to these journals through a family portal, which also stores medical and contact information for the patient. This information can be very important. For example, once when a user fell and paramedics were called, the human caregiver did not have vital information to give them.

However, the avatar on the screen, a dog, provided the paramedics with the necessary information.

Jamie Titak, who works in the healthcare interactive field, gave her 92-year old grandmother a special Christmas present this year — a new friend, named Andy. Andy is a dog that talks to her grandmother about her childhood home in Indiana and her pony. Andy knows the names of family members and friends who visit and tells her when to take her pills or go to the bathroom. At night, when Titak's grandmother is sleeping, Andy wakes up when he hears a noise and checks for any problems. Titak says, "My grandmother likes it. So does my mom, who is her caregiver. It is hard to find things for my grandmother to do. Andy is a constant presence."

Gerijoy offers personalized music therapy and the avatar can show patients their family pictures, asking, "Hey, your daughter sent us a new picture. Do you want to see it?" Avatars speak in English and Spanish, and the company is contracting with a government-funded organization in China to offer Gerijoy in Mandarin and Cantonese. For more information, visit: www.gerijoy.com.

Pixie-Scientific: The germ of the idea began in a diaper belonging to a crying one-year old in the backseat of her parents' car. Maybe she needed a diaper change, or worse, maybe she was sick. "What's in her diaper?" Her worried mother Jennie Rubinshteyn repeatedly asked her husband, Yaroslav Faybishenko, who replied, "Data is in her diaper. Urine is full of so much health information."

His comment got the couple thinking. All that data, and people just throw it away. They did the math: 10 million kids wear diapers, and more than twice that number of older adults wears diapers too. In their research they found that urinary data could be used to identify urinary tract infections, a big problem for both the young and old. The couple created a monitor in a portable diaper that flags the infection just as it starts brewing. The alert on the monitor

can then be scanned by a smartphone into an app, which registers any sign of infection or dehydration, another problem for those with cognitive impairment, in less than 10 seconds. The company is going through safety and efficacy studies necessary for Food and Drug Administration approval of new devices. For more information, visit: www.pixiescientific.com.

SingFit: People with dementia may forget what they just heard or said, but sing an old tune and you see life stirring to the surface. The idea behind SingFit, an iPad-based musical health program, is to get people singing, remembering, and connecting.

There is a lot of science behind music therapy and its effects on the brain, showing that it strengthens cognitive function and mood. SingFit is used successfully in senior care communities, skilled nursing facilities, and adult day programs. The company is now working with caregivers to bring it to private homes.

Andrew Tubman, Co-Founder and Chief of Therapeutics and Music at SingFit, says, "There are so many benefits of singing. It is proven to be a whole brain workout, help with mood, and keep the brain active. Musical processing is often the last thing a person with dementia loses."

SingFit doesn't just play songs, it has a guide singer on one track and a lyric coach on another. They prompt listeners with the words before they need to sing them, encouraging spontaneous and successful engagement without being tied to a lyric sheet. The app also allows people to record their own voices in place of the singer, and then share the new renditions of the songs with family and friends through the internet.

SingFit PRIME™ is a cognitive stimulation program designed to be used one hour, three times a week in senior care communities with trained staff that includes trivia, movement, and multisensory stimulation. Tubman hears from staff in senior care communities that it helps to elevate mood, diminish sundowning and agitation, and refocus

attention, saying, "Active music making that includes singing is different from passive listening in that it keeps the whole brain and body exercised and active." The company offers training to caregivers in senior care communities and education for caregivers at home, in addition to an app that allows users access to the company's playlist and a handful of free trial songs. For more information, visit: www.singfit.com.

Jeffrey Kaye, M.D., is an endowed professor of neurology and biomedical engineering at Oregon Health and Science University. He uses unobtrusive in-home monitoring systems to study physiological and biological parameters that might offer hints about why some people are protected against dementia and functional decline even when they have risk factors. Dr. Kaye observes participants' movements and sleeping patterns with infrared motion sensing devices. Dr. Kaye also places sensors on their pill bottles to keep track of how many times a day they are opened, and monitors their physical health and telephone and computer usage. He evaluates this data and uses it to predict if a person will be in a nursing home in six months saying, "These measurements will allow us to fundamentally change the way we approach assessment."

"The biggest challenge is that there is little evidence to guide people to what actually works," said Dr. Kaye. Safety is always a big concern. "As people become more severely impaired they may wander off and can't find their way back. These devices have to be worn or carried and charged, so they might not be as practical for people in late stages of the disease living at home."

Dr. Kaye mentions PARO the talking seal, which has gotten a lot of media attention. "I'm a high-tech guy, but I feel we ought to have more frequent human contact... We make a lot of assumptions but we just don't know. There are so many devices but we don't know how best to guide the public to use them."

My older brother was diagnosed with Alzheimer's disease in 2011. Lately, it has become harder to care for him as he requires more assistance. I find myself becoming more isolated and alone. How can I stay connected?

- Jessie



Stephanie Aragon
Manager, Helpline
Helpline@alzny.org

Caring for a person with Alzheimer's disease can be overwhelming at times. Family caregivers often have to juggle multiple responsibilities while still caring for the person with dementia. You as a caregiver may worry about issues such as safety and whether or not the person with dementia is eating and bathing. The person with dementia may be up at night. Financial concerns are ever present. Family caregivers frequently report feeling isolated because they need to balance these competing concerns.

The Alzheimer's Association created ALZConnected®, an online social networking community designed specifically for people with Alzheimer's disease and their caregivers. ALZConnected is free of charge and offers features found on many popular social networking sites. Once you join ALZConnected, you can connect and communicate with people who understand your unique challenges. As a member, you can determine which functions best meet your needs and you can share as little or as much as you want.

Another advantage of joining ALZConnected is that you are connected to people in similar situations as yourself. You can create private groups to connect with other members to share your experiences. You can also pose questions related to dementia, for example:

- What about me, the caregiver, and my own needs?
- Should I let my brother drive and how can I stop him?

- May I disclose my brother's diagnosis to friends without his permission?

ALZConnected members respond with their experiences and offer solutions. Members can create public and private groups organized around a dedicated topic and contribute to message boards.

ALZConnected, like other web-based programs, can be helpful, but nothing replaces a live person. Take advantage of our services! The Helpline is available around the clock, 365 days a year. You may be overwhelmed by the diagnosis of dementia that the doctor has just given, and not know what to do first. You may feel helpless and depressed. When you call the Helpline you can get practical information on a number of topics, such as finding an aide to come to the home for a certain number of hours per day, or get referrals to day care centers that can offer your brother activities, lunch, and transportation, and provide you with some much needed respite. You can also receive information about managing difficult behaviors associated with dementia. Calls are answered by staff who are able to provide the support you deserve.

You may want to take advantage of our Care Consultation services, where you meet with a licensed social worker either alone or with other family members to get assistance in planning for your brother's care. Care Consultation is an in-depth, personalized service for individuals and families who are facing many decisions and challenges associated with Alzheimer's disease and related disorders. The goal is for each family

to develop a better understanding of the disease, make a plan to secure needed help, and develop strategies for the best possible symptom management and communication. Consultations are provided in person, by phone, and via email.

The NYC Chapter also offers close to 120 support groups for caregivers. Groups are provided to adult children, daughters only, spouses only, or mixed groups. Small groups of about ten people meet regularly here at our Midtown office or in community partner agencies around the city. Members are provided with a safe place to discuss the challenges of caregiving, share their feelings, and find emotional support. You can share things that you might be embarrassed to bring up with family members or friends. What is said in the group is confidential. Group members also exchange practical information such as how they deal with eating issues or incontinence. Members and/or the group leader may recommend books that they have found helpful.

You can call us for emotional support as often as you need. Remember, we are here for you throughout your caregiving journey.

**The 24-hour
Helpline is
available around
the clock, 365
days a year.
800-272-3900**

Every iPod Brings a Lifetime of Memories



By Dave Roth

“Everything has gotten too complicated these days!” That is the familiar sound of my father. You see, he is a man in his early 80’s who was born in a time fresh off the Great Depression and in the infancy of great technological discoveries. As time marches forward, we find that advancements in technology are no longer coming in terms of years or months, but rather at lightening speeds. By the time you learn of a new breakthrough, they are already developing and releasing the latest and greatest device. To some of the elderly, these changes are confusing, frustrating, and downright frightening — even more so to someone living with Alzheimer’s disease.

But Dan Cohen, MSW, founding Executive Director of Music & MemorySM, saw this as a gateway to breathe life back into those lost in the recesses of their own minds by reawakening their memories. Dan is a trained social worker with a background in technology and realized there was a perfect marriage to be had between both interests. “Ten years ago I heard a journalist talking about how iPods are ubiquitous and I thought, well all the kids have them, but a lot of adults don’t. My experience in the nursing home didn’t seem to involve music. I began to wonder if I was ever in a nursing home, would I have

access to my favorite 60’s music? So I Googled iPods and nursing homes, and even though there are over 16,000 nursing homes in the U.S., I couldn’t find one that was using iPods for the residents.” So he set out to see if this modern technology could be used in a widespread format. Dan’s work has been widely documented in a viral YouTube clip with over 7 million views of Henry, an elderly man with Alzheimer’s, that reawakened while listening to music of his youth. This is part of the award-winning documentary *Alive Inside*, which follows Dan’s use of this therapy. Dan discovered that just listening to any type of music would not produce these reactions, but specifically listening to music that related to one’s past could. “Music has to have personal meaning to them, and that’s really where you are reaching back into that part of one’s memory that is still very much intact. Our love of music is emotional and not cognitive.” Not only was this effective for the person with Alzheimer’s, but also incredibly therapeutic for their family, as they were able to share their own memories while compiling the person’s favorite music.

Seeing Dan’s documentary personally inspired me to bring my mom her favorite music, as she was also in the throes of Alzheimer’s and had lost

her ability to speak. My family and I were moved to tears to hear her once again singing words that we thought were lost forever. I, with so many throughout the world who were beginning to use this technology, was quickly inspired to spread the word. This is where the gift of modern technology comes into play. With an iPod, we are able to download a world of music on this tiny device. Specifically, the iPod Shuffle’s simplistic design makes it easy for not only for those with Alzheimer’s, but also for the countless caregivers, to use. With just one click, a door to the mind suddenly opens and reconnects a person with Alzheimer’s to their own memories, and also, once again, to the people around them.

Music & Memory has brought their work to nursing homes all over the world. Entire state health agencies have endorsed this therapy to be used throughout all their elderly facilities. Most significantly, Wisconsin’s Department of Health Services reported a dramatic decline in the use of psychotropic drugs after implementing Music & Memory’s personalized

music program. This inspirational program is also inspiring grassroots efforts to raise funds and donate used iPods all over the nation. My personal experience with my mom called me to action and I formed the Broadway Alzheimer’s iPod Drive, which is now in its fourth year. We have collected hundreds of used iPods and continue to bring awareness to this devastating disease. Brilliant minds have created technology that can reconnect broken minds. The irony is cruel but beautiful, and only inspires us to find even more ways to care for those who deserve so much more.

For more information visit www.musicandmemory.org and www.facebook.com/BroadwayAlzheimersiPodDrive.

Dave Roth is a Broadway musician and an Alzheimer’s advocate.



This Is Our Cause



Candace Douglas
Director of Constituent Events
CDouglas@alznyc.org

For team Athletes to End Alzheimer's, the year is bookmarked by two signature New York City running events: the 2015 United Airlines NYC Half and the TCS New York City Marathon. The team literally starts and finishes each year in their running shoes, bidding adieu to and ushering in winter respectively. The image is fitting. As a team, our mission is to run Alzheimer's out of our town, and out of our world. What better place to start than at the crossroads of the world: New York City. This year's half marathon team has already gotten ATEA off to a great start by raising over \$100,000 for the Alzheimer's Association, New York City Chapter in support of programs, services and research.

For almost three months, our team trained with one physical mission: take over the streets of Manhattan and complete the half marathon. However, their mental mission goes far beyond that. On March 15, for this crop of runners, whether this was their first long distance race or their 30th, they

competed with the knowledge that each time they pounded the pavement, they brought us one step closer to the end of the disease. During this winter, where the snow piled on endlessly week after week and this February was the coldest on record in almost 80 years, the team's drive and determination never lessened.

Running is simultaneously an incredibly individual and social sport. Runners compete against each other, but they also compete with themselves to beat personal records. You can run alone on a treadmill or in a park at the crack of dawn. But you can also come to a team practice and make a new friend who will forever know you at your physical best (and possibly worst, after a particularly tough run). Interestingly, this duality resonates strongly for many of our runners in their roles as caregivers. Alzheimer's caregivers can often feel isolated, and yet their stories are similar to the over 15 million caregivers providing unpaid care across this country. And sometimes, by connecting with your "team," or for caregivers by sharing their burden with others, joining support groups or reaching out to their local Alzheimer's Association Chapter for assistance and education, they can elevate an incredibly tough

moment in their lives into one of empowerment. They can become educated caregivers. They can speak up as advocates. They can raise awareness in their streets and among their connections. They can become a movement.

Co-founder of the NYC Marathon Fred Lebow once said, "In running, it doesn't matter whether you come in first, in the middle of the pack, or last. You can say 'I have finished.' There is a lot of satisfaction in that." Team Athletes to End Alzheimer's knows that the fight against Alzheimer's disease will not be easy, but they look forward to the satisfaction of seeing it end. Whether they are running (United NYC Half and TCS NYC Marathon), cycling (TD Five Boro Bike Tour), tri-sporting (New York City Triathlon) or playing football (Blondes vs. Brunettes®), every year athletes young and old take up the baton and keep the fight going. They know that one day soon, victory will be in sight. These are our streets. These are our loved ones affected by this devastating disease. This is our cause.

If you're interested in joining team Athletes to End Alzheimer's, please contact athletes@alznyc.org or visit www.alznyc.org/athletes.

Junior Committee Update

By Marielle Mindlin Bernstein
Junior Committee President

The Millennial generation invented social media and now we're using it for social good. Many people have the misperception that all that is shared on social media are narcissistic statuses and selfies, and although there is a lot of that, there is so much more. Social media feeds these days are filled with interesting articles, thought-provoking video clips, and fundraising campaigns. The Junior Committee uses its social networks to provide insight, information, awareness, and opportunities to hundreds of followers.

We use our social media as a news outlet and as a way to spread awareness among our generation. Young professionals are extremely busy, as the 40-hour work week is something we've never known. It can be challenging to keep up with the latest news about Alzheimer's. That's why we do the heavy lifting of sifting through the news (with much help from Google Alerts) and picking out articles and videos that we think will resonate with our followers.

In addition to sharing articles, we share facts and figures on a regular basis. The thing about Alzheimer's is that the facts speak for themselves — when you see the numbers you immediately understand the crisis at hand. Putting those numbers out there on a regular basis helps our generation to stay in tune with what we are facing. And this problem is what our generation

is facing — the numbers today are staggering, but the estimated numbers for 30 years from now are even more horrifying, and we are the ones that are going to have to deal with the effects of those numbers. Social media is an easy way for us to share those numbers and spread awareness about what we'll be facing if nothing changes with regards to a treatment or a cure.

The instantaneous reach that is possible when you post on social media allows us to reach hundreds of people with the single click of a post button. Every time we "Share" a fact about Alzheimer's or an interesting article, it is seen by our hundreds of followers. And every time one of our followers "Likes" or "Shares" it, the post is then seen by their hundreds of followers, and so on and so forth. Then before you know it, thousands of millennials have started an online conversation about Alzheimer's — an "old person's disease."

It's also easier for a lot of people to share Alzheimer's related news behind their computer screens, rather than bring it up in conversation. A person may not want to talk to their colleagues about their weekend visit to their grandparent who didn't know who they were. However, that same person may feel more comfortable "Liking" or "Sharing" one of our posts on Facebook. Social media facilitates the conversation that many have trouble having in person.

But there are times when millennials are looking to have the difficult

conversations about Alzheimer's with their friends and families, yet there seems to be a lack of guidance on how to handle these conversations. One of our members was frustrated during the holidays because she didn't know how to explain to her friends that she couldn't join all the festivities with them and leave her mom at home alone. And when her friend suggested that she "bring her mom along," she realized just how little her friends understood about the situation. She wished she had some guidance about how to talk to her friends about what it is actually like to have a parent with Alzheimer's.

This conversation inspired the Junior Committee to start a blog where JC members could go for information about how to talk about Alzheimer's, as well as share their own advice and experiences. Our hope is that our blog "Alz Talk" will enable and facilitate conversations about the disease. The first blog post, "Why is it so hard to talk about Alzheimer's?" kicked off the discussion. The blog has grown to include interesting facts and articles that people may want to talk about, as well as personal stories from Junior Committee members.

Join our conversations by liking our Facebook page (www.facebook.com/juniorcommittee), following us on Instagram and Twitter (both @alznyjc), and visiting our blog (alztalk.tumblr.com). We need to keep Alzheimer's on top of mind, and social media's the way to do it.

Are you a young professional looking to get involved?

Join the Junior Committee today!

www.alznyc.org

Navigating Safety and Technology



Julio Rivera
Spanish Outreach MedicAlert® +
Safe Return® Associate
JRivera@alznyc.org

Three out of every five people with Alzheimer's will wander during the course of the disease. While we can lock doors and be vigilant, we cannot prevent every instance of wandering. If a person with Alzheimer's lives alone or a caregiver works or travels, wondering where they are can be stressful. This is where technology can help.

GPS (Global Positioning System) technology is now ubiquitous. It's in every smartphone and included in new vehicles. GPS-enabled devices receive their precise location from satellites orbiting Earth. With A-GPS (Network Assisted GPS), cellular networks are used to increase the accuracy and speed of positioning information, as well as provide location information indoors, where unassisted GPS is seldom effective. Alzheimer's Association Comfort Zone®, powered by Omnilink, uses these technologies to allow caregivers to track, find, or follow their person with Alzheimer's while providing persons with Alzheimer's the independence to move about freely. Comfort Zone allows a caregiver to monitor the location of a wanderer from any computer. Devices can be worn on a lanyard, placed in a pocket, or mounted in a car.

However, manually tracking the location of a person with dementia at all times of the day is not practical, and may not help relieve stress. Because of this, Comfort Zone alerts caregivers by email or text message when a person has traveled outside of previously designated "safe" zones. Three "safe" zones can be selected, for added flexibility. Knowing that one's relative is safe at home from anywhere offers caregivers peace of mind. Comfort Zone offers a variety of options.



For more information, visit:
www.alz.org/comfortzone/.

Sometimes, a low-tech approach is just as effective. I have seen cases in which a wandering person with Alzheimer's is found by a good samaritan and reported to us even before their caregivers were aware they were missing.

MedicAlert® Foundation makes identification bracelets and pendants for people with various medical conditions. In 2006, the Alzheimer's Association partnered with MedicAlert Foundation to create MedicAlert® + Alzheimer's Association Safe Return® (MASR). Persons with Alzheimer's disease wear MASR bracelets or pendants, which include basic information — a first name, a phone number, an ID number, allergies, and the most pressing medical conditions — that will help reunite the person who has wandered with his or her caregiver.

Why use a low-tech bracelet with only basic information and not a GPS? There are many benefits to the MASR program. The first is no reliance on batteries. Batteries require charging, and a GPS device with dead

batteries is of no use. The second is permanence. A MASR bracelet remains on the person's wrist all day and night and is difficult to remove. Often, wanderers leave their home without proper attire, sometimes even without shoes, let alone a GPS device! We recommend the MASR bracelets instead of the more easily removable pendants for that reason. Fortunately, Comfort Zone includes membership into the MASR program.

The greatest benefit of the MASR program is the network of people who work tirelessly to help ensure a prompt and safe return of those who wander. When a person with Alzheimer's wanders, it is essential to search the area where they were last seen and call the police. The New York City Chapter works closely with the Missing Persons unit of the New York Police Department. We send out missing person bulletins to New York City hospitals, shelters, and other organizations, post the relevant details on our social media channels, and employ a public relations firm to help alert the media.

Once a person is found, the first responder can call the number on the ID bracelet and receive relevant and possibly life-saving medical information. For more information on MedicAlert + Alzheimer's Association Safe Return, visit www.alznyc.org/masr.

Technology can improve safety, independence, and peace of mind, but it works best when complementing a dedicated network of individuals working together to support people with Alzheimer's disease and their families.



How Technology Has Transformed the NYC Chapter



Asif Baksh

Vice President, Director of IT and Digital Media

ABaksh@alzny.org

August 2015 marks my tenth year at the New York City Chapter. During this time, not only has the Chapter nearly tripled its staff, we've expanded our footprint by acquiring an additional floor to serve our community and creating satellite offices in other boroughs.

Just as Silicon Valley has transformed various facets of society, nonprofit technology is causing ongoing transformations, from the way supporters engage with their chosen organization to the way nonprofits fundraise, market, and manage information. The NYC Chapter has benefitted from these exponential growth opportunities in many ways, ranging from various fundraising successes to cultivating donors online and even finding new communities of supporters. As a result, our mission and outreach can be executed in a very efficient and scalable way.

The NYC Chapter employs a variety of cloud-based and software solutions to track donors, fundraise online, manage data, and enhance programs and services. Our technological blueprint can be outlined as:

- **Operations:** technology solutions manage daily operations, including software applications, automated processes, business continuity and disaster recovery, network reliability and security, staffing upgrades, capacity planning, and policies, procedures and documentation
- **Constituent Management:** software and procedures for managing client, donor, and constituent information, as well as relationships and data collection standards
- **Marketing:** technology as a marketing tool, an interactive

and updated website, and consistent messages among web and print communications

- **Communications:** electronic newsletters, email blasts, and social media
- **Fundraising:** automated, integrated fundraising applications and event management



- **Service Delivery:** technology integrated into education programs and professional training, mobile computing, and research and development
- **Reporting:** meeting reporting requirements and conducting organizational, financial, management, and board reporting with advanced tools
- **Training & Education:** technology training and education plan for staff, including documentation of skills and matching skills to job requirements

While the NYC Chapter remains a separate entity under the umbrella of our National organization, we have spearheaded many initiatives that have been adopted by other Chapters across the country. One such example is the MedicAlert® + Alzheimer's Association Safe Return® program, which was created locally and has expanded nationwide with a 99% success rate. Another example is a resource that we created for our trained professional caregivers to help them connect with families looking

to hire private home care workers, Together We Care™. In both cases, technical expertise is crucial to the programs' success.

Looking Ahead

As new technological trends emerge, the NYC Chapter looks forward to building more socially connected resources. Some of these trends will have the biggest impact on:

- **Mobile:** More than 50% of emails are now read on mobile devices, thus having a mobile-friendly approach to engaging donors is key. Mobile devices are becoming a platform for computing and collaboration, and their prevalence will change how the organizations leverages data and drive mission goals.
- **Analytics:** Data is the key for nonprofits to understand what communication channels are most effective, how to better fundraise, how to effectively facilitate events or peer-to-peer fundraise, and how to increase recurring giving. The ability to pull analytics from software is paramount to fundraising.
- **Cloud:** There will be less need to maintain applications and data in-house when utilizing the cloud is far more cost-effective, accessible, and provides higher quality service. Many major technology companies offer deep discounts to nonprofits that utilize their cloud solutions.
- **Software:** Information and functionality will be available to users in any environment on any device. This will also accelerate a move away from on-premise installations of software to software-as-a-service/cloud-based implementations.

Technology is most sophisticated when it is integrated into daily life without being apparent. This is what we, as IT administrators, strive for.

An Interview with Julianne Moore



Matt Kudish
Senior Vice President of Caregiver
Services
MKudish@alzny.org

Matt Kudish (MK): Congratulations on your Academy Award!

Julianne Moore (JM): Thank you very much. It's super exciting.

MK: It was really exciting for us too. The film is raising awareness and your performance was incredible.

JM: I have to say, I owe a huge, huge debt of thanks to everybody at the Alzheimer's Association, certainly nationally, but particularly in New York City. Everyone was incredibly generous with their time and their information; all of you who work there, the social workers and the clients. All your clients were helpful, particularly the early stage group. I hope they know that a lot of the very specific language that I used in the movie was taken directly from the conversations I had with those women.

MK: That's so nice to hear. How was your preparation for this role different, if at all, from preparation for other roles?

JM: If you don't have any personal experience with the subject matter, you just study it as intensely as possible. What was unique about this was the amount of work that was necessary because it's such a huge subject. And I think there were things that I needed to do. I needed to do the emotional work. I also needed to do the physical work. So there was a lot of reading, there was a lot of observation, and physical behaviors that I had to figure out. And that being said, there was also a broad range of behaviors.

With every role, you have to work really hard to try to get it right. But with this one in particular, I felt an enormous obligation to be as correct as possible, because this is something that people are living with every single day.

MK: Did you feel any extra pressure to get it right because of all the attention around the book, the film, and the number of people who are affected by the disease?

JM: I felt pressure because I felt like I had an obligation to the people who are living with this disease. This is not something I wanted to represent inaccurately. When something was vague on the page, and our directors said, "Well, you're just looking out the

window, or whatever." I said, "No, I do not want to do anything that I have not actually seen with my own eyes." I think there's a misunderstanding about Alzheimer's that people just zone out, kind of look away. But that's not what I saw. When I observed people, I saw them working very, very hard to be present. So rather than someone disappearing, I found people working hard to connect, to work their way through the fog.

MK: Was that a surprise to you?

JM: It was. Because I had no experience with Alzheimer's. None. I'm one of those very, very rare individuals who has not had a family member dealing with this disease. So, all of it was brand new to me.

MK: It's fascinating, really, because it's rare these days for someone not to have had a connection. And then, for you to be charged with this enormous task of getting it right.

JM: I had the benefit of Lisa Genova's book, *Still Alice*. The book is so spot-on with a lot of the symptoms and the emotions and it was a great guide.

MK: There are so many assumptions that people make about people with Alzheimer's disease. I don't think most people recognize how high-functioning and how independent people are in the early stage of the disease.

JM: I think that one of the tragic things about Alzheimer's is that people think you're diagnosed and that's it. But the early stage can go on for a very long time, and people are high-functioning and have good days and bad days. And on the good days, they really do feel like they're completely normal. And on the bad days, they're really struggling.

Even the way it was described to me; that getting lost is more akin to a panic attack than it is to, "Do I go left or right?" I remember one woman

telling me that she remembered being in the shower, looking at the shower handle and knowing that that's how she got out, but not knowing what she was supposed to do with it. Was she supposed to touch it, push it or pull it?

MK: That's such a good example of the kinds of challenges people in the early stage struggle with.

JM: And I loved how she described it to me. That sense of something in your brain not working and trying to work around it.

MK: Have you gotten any feedback from the Alzheimer's community since the film's release and your Academy Award?

JM: Oh, absolutely, from lots of people. Certainly, I've stayed in touch with the women I met and love. They really felt seen and represented. And not just here, not just in this country. When I went to London and we premiered the film there, there were several people who were living with Alzheimer's who came to the screening, and I talked to them about their experiences. They are all in the early stages and said that they couldn't believe how much it represented their experience. It's been great. And that's the thing. As an actor, you just want to get it right for the people

dealing with it, because if you haven't gotten it right, it's not a real story.

MK: When you're in the middle of filming, how do you keep track of where you are in the story?

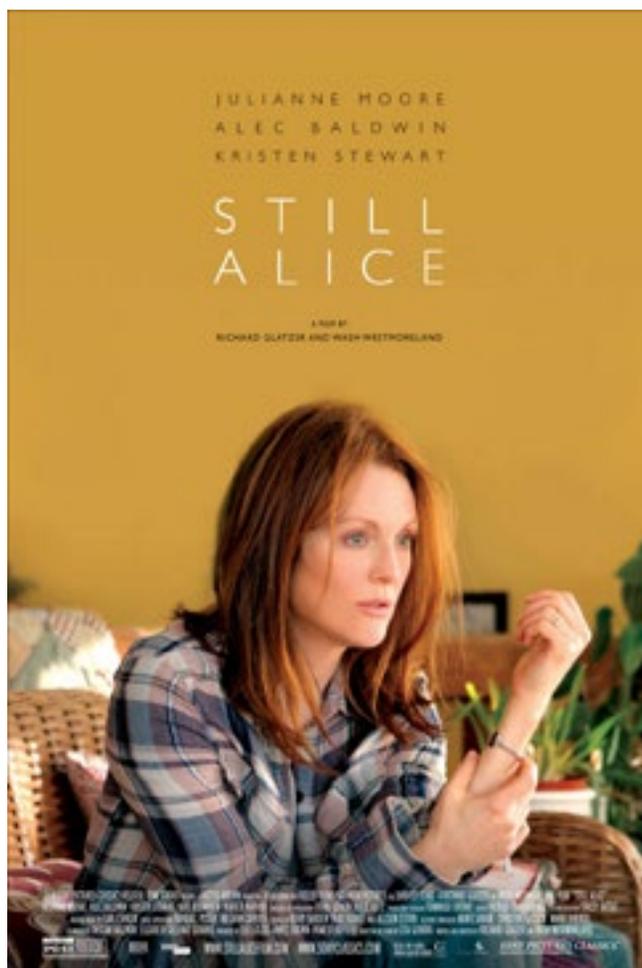
JM: You never film in order on a movie. You film by set. So you do all of the scenes in one location and then you move to the next location and the next location. In this case, Kristen (Stewart) and I filmed the last scene of the movie, the very, very last scene on the ninth day of the shoot. So, we hadn't done any of the beach stuff. We hadn't done any of the middle part of the movie

MK: So in a film where you're portraying someone with a progressive illness, how do you know where in that progression you need to be for each scene? In other words, how do you know you're getting it right?

JM: You don't know you're getting it right. As an actor, you have to kind of track the emotional progression and the physical progression, even if you're not dealing with a true story. Finding a way to do this is part of the job. In this case, I just had to hope for the best.

MK: Well, whatever you did here, it definitely worked. What's been your favorite part of this experience?

JM: One of the things that has been just wonderful for me, is getting feedback from people in the Alzheimer's community. I've been really, really grateful for that. I'm always grateful for the opportunity to meet people that I wouldn't ordinarily meet. I mean,



I think every encounter that you have with another human being broadens your own experience. So, that's been wonderful, eye-opening, amazing, and very, very moving.

MK: Well, you've done a tremendous job, both in the film, but also in helping to heighten awareness for people who may not understand Alzheimer's or what Alzheimer's disease is in the early stage.

JM: I'm delighted that I was able to help.

MK: Thank you so much for all you've done.

JM: My pleasure.

Photo credits: Frederick J. Brown for Getty Images (left). Still Alice film stills courtesy of Sony Picture Classics.





Carol Berne

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

Before launching into spring, I would like to close out our 2014 Year-End Campaign, which ended February 28. With your help, we raised over \$600,000 for much-needed programs and services and research. This was a record-breaking campaign for us, and we could not have achieved such remarkable results without you. **THANK YOU.**

Technology is the feature of this issue, and technology has a significant role and place in fundraising. For starters, *The Chronicle of Philanthropy's* "2015 Philanthropy 50" report, which lists the 50 most generous donors in the country, now includes 12 technology entrepreneurs, double the number from 2013. These philanthropists account for nearly half of all donations, with more than \$5 billion of the \$10.2 billion being donated by individuals on the Philanthropy 50. Bill and Melinda Gates, for example, provided \$1.9 billion to their foundation last year.

In addition to the technology billionaires, and closer to home, we rely upon technology in a number of ways. Our annual Walk to End Alzheimer's®, for example, uses technology to establish a Walker's fundraising page, monitor contributions towards a Walk Team Captain's goal, and help Chapter staff to identify Walkers who may need a boost in reaching their fundraising targets. For our Year-End Campaign, we sent a series of email blasts to encourage last minute donations, reminding donors to maximize their income tax benefits.

Technology enables fundraisers to get a better understanding of donors — the frequency of their giving, what they give to, and how they give. Is their contribution through a private family foundation, a donor advised fund, or writing a personal check? Technology can be an invaluable tool in becoming more efficient, managing operations, and making better decisions. However, technology does not replace the human touch; fundraising ultimately is about building relationships and stewarding those relationships. An email or an email blast will take you only so far; it is connecting one-on-one and learning more about the donor and what motivates their giving, that is the key to a successful relationship between the donor and the NYC Chapter.

In closing, please read our Spring Campaign letter on the next page, written by our new Board member, Jon Henes and his son, Sam. Their letter is a love story for a mother and grandmother. And if you are looking for a special way to honor a loved one during the Mother's Day and Father's Day season, please consider naming a chair in Bryant Park (see p.18). What better way to publicly show your support of our cause and recognize someone special than in iconic Bryant Park, located next to the New York Public Library on 42nd Street and Fifth Avenue?

Thank you. As always, please contact me at 646-744-2905 or cberne@alzny.org if you would like further information on ways to support the NYC Chapter.

Know Your Charity

The following organizations ARE NOT affiliated with the Alzheimer's Association:
American Health Assistance Foundation
Alzheimer's Foundation of America (AFA)
Long Island Alzheimer's Foundation (LIAF)
Staten Island Alzheimer's Foundation (SIAF)
Alzheimer's Disease Resource Center (ADRC)

Ways to Give

Giving by Check

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

Online/Credit Card

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

Appreciated Securities

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

Bequests

By remembering the Alzheimer's Association, New York City Chapter in your will, you can have a significant impact on improving the quality of care for those affected by Alzheimer's disease. Your bequest may have estate tax planning benefits as well. The following is sample bequest language for discussion with your attorney:

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

Life Insurance and Retirement Plans

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

Donor Advised Funds

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

Corporate Giving

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

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

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



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

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

Mother's Day & Father's Day Campaign

May 2015

Dear Friends of the New York City Chapter,

My mother, Karen, is living with Alzheimer's disease. Before Alzheimer's disease took over her brain, my mother was a financial planner. She was a confidant. She gave me advice and hugs and pats on the back. She was a loyal and caring friend, and a loving and devoted wife, mother, and grandmother.

As with all people living with Alzheimer's disease, the mom I knew — the Karen that so many people loved, admired, and emulated — began to disappear. It started slowly, almost unnoticeably. Then, one day it was clear that she was gone. I didn't know how to handle it. I tried to ignore it. I denied it. I tried to act as if it would just go away. It took my 13-year-old son, Sam, to teach me how to deal with this hideous disease.

This past fall, Sam asked me, "Would Grandma remember me?" I responded, "I don't think so. She really doesn't remember very much anymore."

He then asked, "How do you get Alzheimer's disease?" I responded, "No one really knows."

He paused and looked me in the eyes. He said, "I want to see Grandma. Even if she can't remember me, at least I can give her a hug."

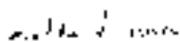
In all the time I was struggling to figure out how to handle the pain from my mom falling victim to Alzheimer's disease, Sam taught me, in that one moment, what I should have known all along — just give her a hug. Just show up. Just be there. Just keep loving her.

And Sam taught me more than that. In January, when it came time for his Bar Mitzvah, in lieu of gifts, Sam asked friends and family to make donations to the Alzheimer's Association, New York City Chapter. With his Bar Mitzvah invitation, Sam wrote:

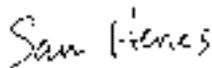
I would like someone to find a cure for Alzheimer's because it is a horrible disease from which my Grandma Karen and so many others suffer. And while a cure is being found, I want to make sure that people like my grandma are cared for and supported. Thank you. Love, Sam

This is why Sam and I are writing to you now. More than 5 million Americans currently live with Alzheimer's disease and far more than 5 million spouses, parents, children, and friends are impacted by the disease as well. There is a good chance that if you haven't been personally impacted by Alzheimer's disease, and while Sam and I hope you never will be, you most likely will. So, Sam and I ask that while a cure is being found, please consider making a gift to the NYC Chapter of the Alzheimer's Association so people like Sam's grandma and their caregivers can be cared for and supported. Thank you.

Sincerely,



Jonathan S. Henes
Board of Directors



Sam Henes



P.S. You can also make a secure donation online at www.alznyc.org/mothersfatherscampaign.

Mothers and Fathers

Husbands and Wives

Partners and Friends

Sisters and Brothers

In Memory of Dad
The greatest there ever was.
Love, Jim Nantz

alzheimer's  association*

WE ALL KNOW SOMEONE WHO'S BEEN TOUCHED
BY ALZHEIMER'S DISEASE.

Mother's and Father's Days are the perfect time to honor, celebrate, and remember the people who helped shape us. Join the over 300 New Yorkers who have dedicated a Bryant Park Memory Chair in honor of their own loved one, and create a personalized message for someone special in your life.

Your plaque will be mounted on one of the chairs in Bryant Park (located adjacent to the New York Public Library on 42nd Street and 5th Avenue), and inscribed with your message and the Alzheimer's Association, NYC Chapter logo. Not only will you contribute to the legacy of a loved one, but your donation also supports the work of the Chapter, helps maintain the beauty of Bryant Park, and raises awareness about one of the most devastating diseases of our time.

Dedicate your chair by June 30, 2015, and receive a copy of our commemorative book, *If This Chair Could Talk* – a special collection of Bryant Park Memory Chair photos and the touching stories of their inspiration. *While supplies last

Visit www.alznyc.org/bryantpark, or call Crissy Vicendese at 646-744-2927 to find out more about the Bryant Park Memory Chair program.

Introducing Together We Care™



Matt Kudish
Senior Vice President of Caregiver Services
MKudish@alzny.org

As we explore technology and dementia in this issue of our newsletter, we are excited to share with you several recent developments with our web-based resource that matches trained home care workers with families looking for professional caregivers.

First and foremost, our resource has a new name: Together We Care™.

The site, TogetherWeCare.com, will function just as dementiaaides.org has, with some major enhancements.

To be sure, Together We Care is the NYC Chapter's site that bridges the gap between home care workers trained by the Chapter through our Dementia Care Training for Professional Caregivers program and family members seeking to hire trained aides.

The initial version of our website allowed for graduates of our training program to create profiles that family members could browse or search for. Based on survey data we collected from both aides and family members, we learned that the site could be even more effective with a few enhancements.

With this in mind, the Chapter is pleased to announce that we have made a number of changes to Together We Care in order to make it as effective as possible.

We hope you'll visit TogetherWeCare.com and take advantage of its new features, including:

- **Post Job Listings**
Family members can now create a job listing for the aides on the site to view and respond to. Take advantage of this opportunity to describe precisely what you're looking for and need in a caregiver

and let our graduates contact you to learn more. Job listings are only viewable by graduates of our training program and are not able to be seen by the general public.

- **Transportation Information**
Profiles now contain information about whether an aide has a valid driver's license.
- **Degrees & Certifications**
Profiles now contain information about degrees and certifications the aides may have, including the institution from which they were awarded.
- **Availability Options**
Profiles now contain days of the week the aides are available for work, as well as whether they are looking for part-time, full-time, or live-in employment.
- **Even More Locations**
In addition to the five boroughs, aides can now indicate if they are able to work in New Jersey, Westchester, Long Island, and Connecticut.

Looking to hire private home care workers?



www.TogetherWeCare.com
can help in your search.

Create a free account, post an ad,
and browse profiles.



Aides are professionally trained by the Alzheimer's Association, New York City Chapter.

Together We Care™

*Connecting trained home care workers
with the families who need them*

Interview with Alzheimer's Researcher Dr. Andrew F. Teich



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

Lou-Ellen Barkan (LEB): Andy, thank you so much for talking with us. Can you start by telling us why you chose Alzheimer's as your area of interest?

Dr. Andrew F. Teich (AT): Alzheimer's disease is the number one cause of dementia, and is poised to become far more prevalent. It's also an intellectually interesting disease; Alzheimer's disease initially affects memory, but can also involve personality and other areas of higher cognition. In a way, understanding these changes and their effects addresses what it means to be human. In addition, we've been working on Alzheimer's for so long that there's both a lot of progress and an opportunity for scientists to make a real difference during their careers.

LEB: It seems to me that being human also means trying to be hopeful, but sometimes hope causes us to speculate based on faith rather than facts. For example, some folks believe that coconut oil prevents Alzheimer's, or that deodorant made with aluminum is a cause. They believe that red wine, antioxidants, and estrogen are effective therapies. Do you think any of these have potential?

AT: I don't think there is any hypothesis that has an unassailable lead over any other, but it doesn't mean that because so many different things are being studied that the field is in disarray. Alzheimer's disease is primarily a disease of aging. As we age, our brains suffer many indignities, and the extent of the damage is affected by genetic predisposition. There are a number of different factors coming together and, given the complexity of this disease, a number of different theories might all be cumulatively correct. For some time, the field was very beta-amyloid-centric. I don't

think we should throw that out completely, but the fact that the field is diversifying is a good thing and a better reflection of the disease.

LEB: A recent article talked about the effect of brain plasticity; the brain's ability to create new neurological connections through physical and mental activity. Yet some people exercise and have active intellectual lives and still develop Alzheimer's. Others do less of both and remain cognitively healthy. Is this a function of plasticity?

AT: That discrepancy is the million dollar question. No one knows the answer, but a lot of people are interested. Unfortunately, there are barriers to solving the problem because whenever you're following people over decades, the work is difficult, costly, and time-consuming. But scientists are trying to answer the question and brain plasticity plays a role. Maybe not in whether you develop Alzheimer's, but at a minimum, how well you can cope with the disease once you have it.

For example, some investigators are studying the correlation between years of education and resistance to dementia in old age. This has created an ongoing debate about exactly what we are tracking when we say "years of education." We know that people with graduate degrees are more likely to end up in jobs where there is a lot of demand on the brain. Scientists assume that these people are also more likely to continue to exercise their brain than those who didn't finish high school or college. But what does this association mean? Does education actually protect you from getting Alzheimer's disease, or are these people just able to withstand a higher degree of disease burden before they start showing signs of dementia? Right now, I think the field is leaning in the latter direction.

LEB: It sounds like there is much research going on and many new ideas. That's why it's been

disappointing that with all the leads, there have been so many expensive drug failures in the last ten years. Have we learned anything from these?

AT: We've learned a lot. When you talk about failure in the Alzheimer's disease field, it's pretty clear that what has failed are many phase three clinical trials of beta-amyloid clearing therapies. But these failures have been real eye openers. There is still overwhelming genetic evidence that beta-amyloid plays a role. As an aside, the culpable protein may not be beta-amyloid itself, but one of several closely related proteins. There is still a lot of evidence supporting the beta-amyloid hypothesis. However, even if the beta-amyloid hypothesis is ultimately validated, beta-amyloid may not be the best therapeutic target. We can now move in new directions, such as learning if beta-amyloid clearance needs to happen earlier in the disease. New studies, directly influenced by earlier failures, are trying to get beta-amyloid clearing therapy to people before they show signs of cognitive impairment. We are going back to the drawing board and attempting to retool. And the field has a greater appreciation for new approaches and new ideas.

I think Alzheimer's is going to end up being a multi-factorial disease, and being open to that possibility in a field as old as Alzheimer's is a sign of strength. I've seen areas of science where you get these very sclerotic hardened positions and nothing happens.

LEB: What about the work that's being done in community studies? Do you think that we will find a larger genetic component for everyone or just for the early-onset form of the disease, where we already know that if one family member has developed the disease in their 30s or 40s, there is a strong probability that other family members will have it as well?

AT: In early-onset cases, there is a strong genetic component. But, in a lot of epidemiological population studies, early-onset Alzheimer's disease is arbitrarily defined as any Alzheimer's that starts before the age of 65. And admittedly, having Alzheimer's before 65 is somewhat unusual, but just because you have someone in your family who got it before 65, doesn't mean you necessarily have one of these extremely rare, familial mutations.

People sometimes say, "My mother got it when she was 65, so I have a 50 percent chance of getting it because it's familial." We need to be careful how we define familial. It really means one of the specific families that have an identified mutation that directly causes the disease. In these cases, people are getting it not just before 65, but earlier, in their 50s and 40s. This only affects roughly 400-plus families worldwide.

Outside this small group of families with true familial Alzheimer's, there are genes that affect the general population. This is being studied in a number of genome wide association studies, otherwise known as GWAS. Some of that work is being done by my Columbia home team, led by Dr. Richard Mayeux. His work has shown that there are a number of different genes that do predispose you to getting Alzheimer's disease, but none of them are deterministic. They just increase your chances.

I think there is a genetic component, but there is also evidence that our DNA gets modified during our lives. This modification occurs differently in different tissues, and there is even different modification in different parts of the same tissue. For example, in the brain, DNA may be modified differently in the frontal cortex than in the hippocampus. These chemical modifications have consequences for

how cells live, behave, and respond. This is being studied in a hot new field called epigenetics, which is very encouraging and is adding a new level of thinking. There's a lot of promise in looking at the genome, not just generally, but also specifically: how the genome gets modified locally in the brain of those with Alzheimer's disease, and as a result of general aging.

LEB: In the early research on breast cancer and HIV/AIDS, everybody was expecting a "silver bullet," but that never happened. Instead

and try to stave those off or prevent them from having a catastrophic effect.

LEB: That's going to be a major addition to the field, particularly for your generation. In my generation, it's going to be harder to change behavior. The way we think about sustaining good health in our 60s, 70s, and 80s is very different than when we were in our 20s and 30s. Do you think those in their 20s, 30s, and 40s today are starting to think about how to keep their brains healthy?

AT: Young people today are the same as young people since the beginning of time; none of this seems imminent. When you're dealing with a younger generation for whom being 70 or 80 seems very far away, we reach them because they have a family member, usually a grandparent, sometimes, unfortunately, a parent, who is directly suffering from the disease. But their engagement is less about themselves and more about wanting to



we learned about health practices and combinations of therapies — a cocktail approach. Do you believe that this is what Alzheimer's will end up with?

AT: I think a cocktail is likely and that there are two approaches. Both should be pursued. One is how to support and improve cognitive function in people who are already suffering from the disease. The other is to prevent brain degeneration in the first place. I think it's going to be very difficult to reconstitute neurons that have already died. Prevention is much easier than rejuvenation. Ultimately, the Holy Grail should be to understand the multiple environmental insults that move people who are genetically predisposed towards degeneration,

help and honor a loved one. There is a real poignancy to that. The NYC Chapter's Junior Committee members are a great example.

Are there things young people should be doing differently? The environmental influences on Alzheimer's disease are not really clear. But there is a lot we should all be doing. These are the same things our parents told us: don't smoke, stay mentally active, and maintain your cardiovascular health by consuming a heart-healthy diet. As an aside, there has been some controversy recently about the role of saturated fat in cardiovascular disease. Studies debunking the association have received a great deal of press. However, most of these studies are observational, and the American

Heart Association hasn't changed its guidelines; please see the AHA website for more information.

The brain is a vascular organ, so damage to your blood vessels has been shown to affect dementia. And often, people with Alzheimer's disease also have a cerebral vascular disease that seems to affect and accelerate their dementia. There is an ongoing debate about the possibility that vascular disease actually causes or accelerates Alzheimer's disease. Some respected and smart people are making progress in this area, and it may turn out to be meaningful. But regardless of whether it's directly contributory to the disease itself or simply exacerbates the symptoms, maintaining cardiovascular health is one thing we should all be doing for our hearts and general well-being.

LEB: Isn't that also the case for brain trauma caused by a fall or head injury? My doctor once told me that if I want to live longer, I should avoid falling down. For your generation, is there a proven relationship between head injury and contact sports like football and soccer? There is more awareness, but are people taking this seriously enough for themselves and their families?

AT: We've known for quite some time that there is a relationship between repeated head trauma and

neurodegeneration, but we are now realizing that this association may be more widely applicable than initially thought. At first it was thought to be confined to a small number of people who had severe, repeated head trauma over many years, mainly boxers. In the last five to ten years, the field has now accumulated clear evidence of cognitive decline in people who may not have such an extreme history, but still have a history of repeated concussions. Now we are all talking about various activities that can put you at risk for this disease, known as chronic traumatic encephalopathy (CTE). We know football players are at risk, but in addition to contact sports, some members of the military, having been exposed to multiple blast exposures, may be predisposed to CTE.

While many CTE symptoms are similar to Alzheimer's disease, it's currently thought to be pathologically different. What is happening in the brains of these people is being fiercely debated. It's clear that some of them have a unique degenerative condition different from Alzheimer's disease. However, many of these people may in fact also be predisposed to Alzheimer's disease and other neurodegenerative diseases. In any case, it's obviously best to avoid brain trauma.

LEB: It's such a pleasure to hear

how engaged you are. I keep asking myself, "Are there more Andys willing to invest their careers in Alzheimer's research?" I'm told that sadly, research scientists sometimes select fields like weight control because there is substantial grant funding and it is easier to find subjects for clinical trials. We know that Alzheimer's research is challenged with finding adequate numbers of clinical trial subjects, since many are older and already very ill. In the face of these challenges, how do we get more young scientists excited about this work?

AT: You hit the nail on the head when you talked about funding. Given its prevalence, Alzheimer's disease has always been underfunded. You could speculate all day, but I believe one of the big reasons is because people who have Alzheimer's disease are often very frail and not in a position to advocate for themselves like those with breast cancer or HIV/AIDS. The inability of our community to yell and march has handicapped our ability to raise awareness and cost us critical funding support.

When scientists ask themselves, "What am I going to do with my life?" they have to weigh a passion for a specific line of investigation with life decisions concerning themselves and their families. They don't want to end up unemployed because of vanishing research support. Researchers are already afraid they may not be employed in ten years, so when you discuss Alzheimer's disease, and they see the funding isn't really there, they say, "Well, if I'm going to go into research, I'm definitely going to take on something where I'm most likely to stay employed." These are very smart, capable people making life decisions and they need to feel that Congress has their back. Nobody expects a blank check, but at the same time, if you work hard and you publish and you do well, funds should be there for you.

LEB: Years ago, a group of scientists told us that we have enough



Following the January 12, 2015 presentation "Alzheimer's Disease: Current Challenges, Future Hope" (From Left: Chapter Executive VP, Jed Levine; presenter, Dr. Andrew F. Teich; host, Ken Berger; Chapter President & CEO, Lou-Ellen Barkan; host and Board member, Jeffrey N. Jones; and Board Co-Chair, Stephen P. Casper)

buildings and that philanthropic dollars are better spent in the lab. Is that true? Are all of our labs big and modern enough?

AT: It's not spending money on new buildings that is the problem. It's that unless we have funding, we'll have facilities without research scientists to fill them. Buildings are great if you have the people to work in the labs. Columbia's Zuckerman Mind Brain Behavior Institute is a terrific example because we have enough grant-funded neuroscientists to fill it. But there may be other instances where donations are used to support infrastructure that cannot be supported by funded scientists in this age of austerity.

As an aside, there was a huge ramp-up in infrastructure spending at research institutions across the nation in the late 1990s and early 2000s, when the National Institutes of Health (NIH) was at its peak budget. The thought was build it and they will come. Universities built huge research centers and once they had space, they hired scientists who wrote grants, and boom, they had their research center. But without funding, it doesn't make sense.

LEB: How can we influence the new generation of scientists to work on Alzheimer's?

AT: I think young people who are in graduate programs are extremely observant. If, as they are making decisions, they see mid-career faculty having trouble getting grants

renewed, it's a more significant data point than having somebody cheer them on and say, "Don't worry, it's all going to work out."

The larger discussion should be how NIH funding works. Since the NIH began awarding research grants, it's been a competitive process. The major career grant is a five-year grant called the R01. At the end of five years, the NIH evaluates you and if you've made sufficient progress as judged by your peers, you are renewed for another five years. This system worked as long as funding was increasing or at least keeping par with inflation. But when funding didn't keep par with inflation and we still kept churning people out of graduate programs and bringing in post-docs from other countries, the whole system came to a slow-motion crash.

It would be great to wave a magic wand and say, "NIH funding will be restored to its 2003 level and we won't have this problem again." Maybe we need a gatekeeper who follows the scientists and keeps the process competitive, as well as reassures scientists that, if you are above board and doing good work, you will be funded. Reducing the uncertainty of funding would solve the biggest problem.

LEB: When I first worked in politics, I was stunned by how much time people have to spend fundraising. Sadly, it sounds like scientists have much of the same challenge and it shapes the field they select. But scientists, just like all of us, realize

that life is not just about today. It's an ongoing cycle of growth; having a family, paying rent, and doing work they enjoy. Our job is to raise funds to make all of those things possible for you and your colleagues.

Andy, thank you so much for taking the time to talk with us today. It's been both inspiring and informative, and we hope to be with you on the day you announce a cure for Alzheimer's!

Dr. Teich graduated with a B.A. from Cornell University in 1998, and then pursued both an M.D. and a Ph.D. in neuroscience at Columbia University College of Physicians and Surgeons. He continued at Columbia for a residency in anatomic pathology and a fellowship in neuropathology. He was subsequently hired onto the faculty at Columbia where he is currently an Assistant Professor of Pathology and Cell Biology and an Attending Physician in the Division of Neuropathology. In his present position at Columbia, Dr. Teich diagnoses diseases related to the brain and spinal cord and also runs a laboratory where he studies Alzheimer's disease, with an emphasis on identifying new targets for therapeutic intervention. Dr. Teich has received several honors for his ongoing work, including the Gerstner Scholar Award from Columbia University, the Margaret M. Cahn Research Award from the Alzheimer's Association, and an R03 GEMSSTAR award from the NIH-National Institute on Aging. He also holds a New Investigator Research Grant from the Alzheimer's Association.

A story about the effects of early onset Alzheimer's disease on love.

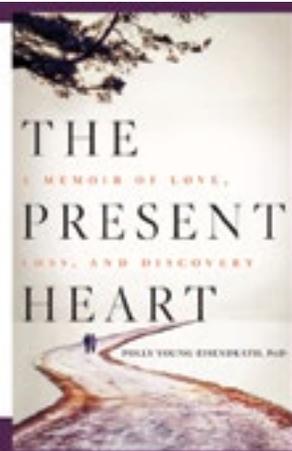
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Technology Can't Replace Face-to-Face Support



Wendy Panken
Manager, Support Groups
WPanken@alzny.org

The New York City Chapter's Support Group program offers Alzheimer's caregivers over 120 support groups each month throughout the five boroughs. The Chapter's support groups have traditionally been offered in both the Chapter office and in community settings. To make this possible, the Chapter enters into partnerships with community organizations who co-host Alzheimer's support groups throughout the metropolitan area.

Whether they are spouses, partners, or adult children, Alzheimer's caregivers generally prefer meeting face-to-face with others because they look forward to the social aspect of attending a support group.

Caregivers go to support groups to share aspects of their caregiving experience they feel they cannot share with friends or family members. It is often reported that friends and family not involved in caregiving ask questions or offer suggestions that, unbeknownst to them, feel critical, judgmental, and shaming.



Ginny Abrams leading a telephone support group

Face-to-face groups offer a sense of community that caregivers need. As Alzheimer's progresses and the person with the disease has more difficulty with his or her memory, finding words, conversing, and relating, Alzheimer's caregivers report that their social lives slow down. Friends and family visit less regularly and the loneliness and invisibility set in. Many caregivers also become homebound with their relative who has Alzheimer's, and leaving home and going to a group enables them to have a few hours to focus on their own needs.

The importance of caregivers meeting directly with each other in secure and consistent support groups cannot be overstated. The effect of actually seeing each other grapple with their feelings is an invaluable healing experience. This experience brings group members close to each other in a way nothing else does. It alleviates the feeling caregivers have of being totally alone and invisible in their sadness and grief. To quote a former group member, "Where else can I cry? Who else but my fellow group members can possibly understand what I'm going through?" Other group members have similarly credited their group experience with changing their lives for the better.

In partnership with several community organizations, the Chapter does offer telephone support groups for Alzheimer's caregivers who, for one reason or another, cannot leave home. These groups obviously function somewhat differently and produce somewhat different results.

According to Ginny Abrams, a group leader who leads both kinds of groups, her telephone support group is a bit more leader-centric and yields more consistent attendance, since it's possible for group members to call in from wherever they are. In a telephone group, Ginny says, the members tend to focus more on her

than on each other. She attributes this to how long it takes to become familiar with each other's voices. For this reason, during the first few months she asked each member to say his or her name before speaking. Over time, the group became close-knit as members increasingly relied on each other for mutual support and guidance.

Initially, Ginny was hesitant about leading a telephone support group, as she felt she had become dependent on the visual and physical cues of an in-person group. "It took me a year to settle into this group, whereas in a face-to-face group I become acclimated within a couple of months. In a sense I was learning to be blind, because I had to find other cues to get to know people without external factors such as their facial expressions, clothing, or hairstyles. I was shocked by a photo I received from a group member, since I had pictured her entirely differently. But after meeting for about five months, I said to the group, 'I feel I can see all of you,' and a group member replied, 'And we're all beautiful!'"

Bottom line, Ginny has shown us that new kinds of groups can provide comfort for caregivers. However, the value of caregivers seeing each other and being able to relate directly as mentioned previously cannot be overstated. It is widely acknowledged that the experience of meeting in-person with others greatly enhances the capacity of group members to relate more openly and honestly in the end, and to cope better with their responsibilities as caregivers.

Interested in joining a support group? Visit alzny.org/supportgroups or call our 24-hour Helpline at 800-272-3900.

Technology & Training



Nancy Lee Hendley
Dementia Care Trainer
NHendley@alzny.org

As we know, there are a multitude of online trainings and YouTube videos designed to educate professional caregivers about Alzheimer's and dementia care. While there are some advantages to learning online, as a Dementia Care Trainer here at the Chapter for the past nine years, I would like to make a case for several important advantages of in-person experiential training.

Professional caregivers greatly benefit from being in a setting with their peers. Many caregivers are isolated as they work in people's homes caring for one client with dementia. This leaves them to face the challenges and difficulties that often accompany the disease alone. It is well known that dealing with people who have Alzheimer's disease requires teamwork. Teamwork is often missing in the case of a professional caregiver. When professionals participate in the Dementia Care Training for Professional Caregivers (DCTPC), they are given a forum to voice their struggles and concerns — sometimes for the first time. The supportive environment created by the trainers and trainees allows for a free exchange of ideas and the possibility to discuss the challenges and successes of this most difficult work. One graduate of the DCTPC remarked that the group environment was important to her because it provided “opportunities to express ourselves — all of our opinions were valued.”

Throughout the training, professionals who have worked in this field for a substantial period of time, some as long as twenty years, are encouraged to share their knowledge and expertise. Their real-life experience is recognized and appreciated. Many of the tips and tools that they share come directly from their experience. As an example, one trainee solved the problem of her client not taking medication by joining her in taking “medication” (in this case, it was

Tic Tac® mints) alongside the client. The aide “took” the Tic Tacs, and the person with dementia took her actual medication. Creative solutions like this example are remarkable and noteworthy. As trainees are able to see the significance of their contributions, their confidence and pride in their work increases.

In-person training allows students to process specific challenges related to their current assignments. Trainees can strategize with one another and the group as a whole to discover innovative solutions to precise challenges that they face.

“Learning should be refreshing and vitalizing. It becomes so only through stimulating exchange with peers with whom one holds discussion. In this way learning becomes many sided and takes on a cheerful lightness. Whereas there is always something ponderous and one sided about the learning of the self-taught.” — The I Ching

Because the training is ongoing, trainees try different approaches and report their failures and their successes. This allows for the constant assessment and adjustment that is necessary in working with people who have Alzheimer's disease.

The DCTPC provides multiple opportunities for hands-on exercises and activities. Some of these activities demonstrate to the trainees what it might feel like to be a person with dementia in certain situations. Our trainees learn by physically practicing the most effective ways to approach a person with dementia so as to have more successful encounters. We know that actual experiences, are in fact, known to be the best and most beneficial practices in adult education. Research has shown that when students interact with others through concrete experiences, the information is more likely to resonate. These types of exercises enhance the likelihood of one being able to incorporate lessons learned in the classroom into their work.

The Chapter is committed to continuing to facilitate live, in-person trainings because we believe this is the most effective way to provide education to professionals so that they can provide enhanced care for persons with dementia. This said, we acknowledge the benefits that technology can bring to the training room. The training team at the Chapter has found Smart Board technology to be extremely useful as an enhancement to our work. Smart Boards allow trainers to add flexibility and personal focus to their presentations. The Boards serve as tools, allowing trainers to

readily refer to an image, concept, or exercise from a previous session. This allows the group to review ideas, build upon group participation, and refresh their minds of already presented important concepts. The Smart Boards give easy access to online resources and websites such as ThisCaringHome.org, Music & Memory, The Alzheimer's Store, and videos by Teepa Snow, Naomi Feil, and many others. The trainers are enthusiastic about the prospect of further enhancing trainings through the use of ever-advancing technology.

An additional way that the Chapter has begun to utilize technology is through the development of Together We Care™. Our web-based resource matches families looking for home care professionals with graduates of the DCTPC.

A healthy balance of in-person training and the use of technology allows the Chapter to engage the “best of both worlds” to provide the highest level of education and training in dementia care.

Is It Time to Buy Into Brain Training? What Every Consumer Should Know

By Cynthia R. Green, Ph.D.
President, Memory Arts LLC
Founder and Lead Trainer, Total Brain Health

Brain training seems to be the latest fitness fad. From TV commercials offering to make your brain “brighter” to “test your memory now” ads popping up on your Facebook feed, evidence of this growing obsession with preserving our neurons abounds. Consumer indicators further support this trend. A 2014 AARP survey found that 93% of those asked feel that maintaining brain health is very or extremely important.¹ This is no secret to the brain fitness industry, where the digital space alone is expected to grow from an estimated \$100 million U.S. dollar market share in 2005 to an astounding \$6 billion U.S. dollar market share by 2020.²

But does it really work? What should the educated consumer know before buying into brain training? And are there any benefits for those who face memory challenges or carry a diagnosis of dementia? What is worth taking a look at? Here is some advice to guide you as you consider whether to invest your time and money in brain training products.

Look to the Science. One of the most significant issues with the current brain training offers is the actual data behind the claims that they make. Some companies have asserted benefits that go well beyond what the science demonstrates, for example, suggesting that using their programs can make your brain “20 years younger” or significantly reduce dementia risk. These misleading claims recently brought together an international group of leading brain science scientists, who published a consensus statement under the auspices of the Stanford Center for Longevity and the Max Planck Institute for Human Development criticizing the

industry for overstating the benefits of software-based brain training.³

What do we know from the science? While this is a young field, there is growing and significant evidence that such products may benefit daily cognitive performance skills such as attention, speed of processing, executive control and memory. However, it may be that the benefit comes from performing intellectually demanding activities against the clock, which characterizes most of these training products. This suggests then that any time-challenge activity, even a board game played with a timer or working on the crossword puzzle against the clock may help us stay sharper with practice. In addition, there is little to no evidence that brain training products reduce our long-term risk for dementia. Best bets? Get in the habit of challenging your thinking with timed activities, whether that brain training is software-based or simply pulling out your old Boggle set and playing against the timer.

If you want to check out brain training software, most companies offer a limited version or trial subscription for free. Look to web- or app-based products, which tend to be less expensive and are easily cancelled. Elevate (www.elevateapp.com), an app-based brain training program which focuses on “real world” training, was recently named 2014 App of the Year by Apple. Peak (www.peak.net) is another brain training app that made Apple’s list. Lumosity (www.lumosity.com) remains perhaps the most popular and successful of the software-based products, and is very user friendly and has a new option to assess your skills. You may also want to consider Brain Baseline (www.brainbaseline.com),

an assessment tool designed to track your cognitive performance over time.

Usability is Key. Another critical factor to consider is the appropriateness of the brain training product for the person using it. While some brain training products may be independently accessed during the early stages of a memory disorder or used with assistance, in general, most of the brain fitness software currently on the market is designed for a younger, cognitively well population and isn’t particularly user-friendly for someone facing intellectual changes. Early research in brain training for memory challenged adults is promising; however, the findings to date are very limited and primarily come from intensive laboratory-based trials. In addition, individuals who were not computer literate prior to a diagnosis face the additional task of learning how to use the technology, which can prove quite difficult.

If you would like to try brain training software for someone with memory challenges, touchpad technology using app-based training products offers perhaps the best option, as the interface is more intuitive and accessible. This is particularly true for individuals with mild changes, or for those who were previously familiar with such technology. In addition, some of the available apps focus on multisensory engagement, such as music, which provides alternative methods for cognitive stimulation. In addition, technological solutions that support independent function, such as medication reminders, timers, location reminders and the like, while not necessarily “brain training,” can be a great tool for mild-to-moderately challenged individuals. The Alzheimer’s

Society in the UK (www.alzheimers.org.uk) offers a very useful review of assistive technology for use in dementia.⁴

Despite the scientific and usability limitations of brain training software for memory-challenged adults, many consumers still wish to try the products, as there is a sense that they “do no harm.” It is important, however, to ensure that the experience is worthwhile to the user and does not become simply a demoralizing and frustrating exercise (which is in fact harmful in its own way). Dakim BrainFitness Silver (www.dakim.com) is a brain training product offered through senior living facilities that has a touchscreen application, although it is not specifically designed for clients with memory disorder. SingFit (www.singfit.com) is a wonderful app designed by a music therapist that uses music for cognitive stimulation and engagement. Memory Apps for Dementia (www.memoryappsfordementia.org.uk) offers regular updates of training and other touchscreen applications.

Balance is Key. Finally, it is critical to keep in mind that despite the hype, brain training is only one of the many ways we must engage to

maintain our everyday cognition and lower dementia risk. Good physical health habits including regular exercise and maintaining a healthy weight, participating in intellectually challenging activities, taking care of our emotional well-being, and staying socially active have all been linked to better brain health over our lifetimes. While we may take this “healthy lifestyle” advice a bit for granted, the science behind it is strong and growing. A recent finding presented at the Alzheimer’s Association International Conference® found that a multi-modal intervention including exercise, cognitive engagement, and lifestyle changes significantly improved cognitive performance in a group of adults at-risk for memory disorders.⁵ This large-scale study is ongoing, but shows that while brain training may capture our imagination, in fact it is how we live day-to-day that might matter most.

Cynthia R. Green, Ph.D. is a clinical psychologist and leading expert on brain health. Known for her ability to provide scientifically solid, practical information on cognitive wellness, Dr. Green is a sought-after speaker and author whose latest collaboration with National Geographic, Your Best Brain Ever, was named a “2013 Top Guide to Life after 50” by The Wall Street Journal.

¹ AARP. Brain Health Research Survey. Accessed 2/20/2015. www.aarp.org/content/dam/aarp/research/surveys_statistics/health/2015/2014-Brain-Health-Research-Study-AARP-res-gen.pdf

² Sharp Brains. Executive Summary: Infographic on the Digital Brain Health Market, 2012–2020. Accessed 2/21/2015. www.sharpbrains.com/executive-summary/

³ Stanford Center on Longevity. A Consensus Statement on the Brain Training Industry from the Scientific Community. Accessed 2/20/2015. www.longevity3.stanford.edu/blog/2014/10/15/the-consensus-on-the-brain-training-industry-from-the-scientific-community/

⁴ Alzheimer’s Society. Assistive technology – Devices to help with everyday living. Accessed 2/20/2015. www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=109

⁵ AAIC Press Release. Two-Year Clinical Trial of Multifaceted Lifestyle-Based Intervention Provides Cognitive Benefits for Older Adults at Risk of Dementia. Accessed 2/20/2015. www.alz.org/aaic/releases_2014/mon-730pm-finger.asp

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2015 Ushers in Alzheimer's Advocacy Success



Hillary Stuchin
Director of Public Policy
HStuchin@alzny.org

So far, 2015 has been an incredible year for Alzheimer's advocacy efforts. From Capitol Hill to Albany and City Hall, Alzheimer's disease is being recognized as a major public issue and health crisis that can no longer be ignored, thanks to the commitment and enthusiasm of advocates and supporters.

On February 24, the New York State Coalition of Alzheimer's Association Chapters, of which the New York City Chapter is a member, held its annual Rally and Legislative Visit Day. Nearly 200 Alzheimer's Association advocates, Ambassadors, and Chapter staff from across New York State traveled to Albany to urge elected officials to support increased funding for Alzheimer's care and support services statewide. These efforts paid off. On April 1, New York State took a major step forward in its support with the inclusion of \$50 million for care, support, and respite services statewide. This funding — the largest one-time increase by any state — is committed to serving all New Yorkers living with or caring for a person with Alzheimer's or related dementias. This support helps address the dire need for services, which until now had been funded at just over \$1 million statewide.

To further inspire support, this time on the national stage, more than 1,000 Alzheimer's advocates and Alzheimer's Association Champions travelled to Washington, D.C. in late March for the annual Alzheimer's Association Advocacy Forum. The Forum, a three-day event, features influential speakers who are committed to enhanced care services and increased research funding to find a means of preventing, treating, or curing Alzheimer's. This year's keynote speaker Dr. David Satcher, the 16th Surgeon General of the United States, is thoroughly committed to our cause as the primary caregiver for his wife

who has Alzheimer's disease and a pillar of the medical community. In his address, Dr. Satcher inspired Forum attendees in a call to action, saying "Let's get it together; let's band together; let's educate and motivate. Let's get the right policies in place to deal with this problem."

Echoing Dr. Satcher's call for increased funding for Alzheimer's research and enhanced care services, the Alzheimer's Association's 2015 Federal Priorities include the passing and enactment of the HOPE for Alzheimer's Act (S.857, H.R. 1559) and \$300 million in additional funding for Alzheimer's research at the National Institutes of Health (NIH). Both items are consistent with recommendations laid out in the National Alzheimer's Plan.

New York City Chapter Ambassadors, advocates, Junior Committee members, and staff then stormed Capitol Hill to meet with our Congressional representatives. In each meeting, Congress Members and their staff met our requests with great support and encouragement. Advocates shared their personal accounts of caring for family members with Alzheimer's disease and the impact the NYC Chapter has had on their lives as caregivers. A highlight of our Capitol Hill visit was meeting Senator Chuck Schumer, who personally pledged his continued support.

The achievements of Alzheimer's advocates and supporters cannot be overstated. While the New York City Chapter is committed to enhancing care and support services in addition to increasing research funding for Alzheimer's disease, we could not continue to make an



New York State Advocates hold annual Rally Day in Albany
Credit: NYS Coalition of Alzheimer's Association Chapters



New York State Advocates meet with Senator Chuck Schumer
Credit: NYC Chapter

impact on our lawmakers, at any level of government, without the efforts of our advocates and supporters.

We have seen amazing success in recent years. Since 2012, Congress and the President have increased the budget for Alzheimer's research at the NIH from just over \$400 million to nearly \$600 million. While this incremental funding is not as high as we need it to be, it does show that our lawmakers are listening and starting to understand the monumental impact of Alzheimer's disease. They know that if they do not support efforts to find a means of prevention, treatment or cure, our national spending on the disease — currently \$226 billion annually — will skyrocket to \$1.1 trillion annually by 2050. Even in a divisive climate, Congress can come together on issues that impact us all.

Technology and Advances in Alzheimer's Research

As the number of people affected by Alzheimer's disease increases, due to the aging population, the need for better therapies has become increasingly urgent. Technological advances are also increasing, so it is natural to ask: how can these advances accelerate the development of Alzheimer's research? Indeed, researchers are harnessing new technologies to improve research methods in several ways. These techniques may provide less invasive diagnosis, in addition to better markers of progression, allowing determination of the effects of experimental therapies to be seen earlier and requiring fewer research subjects. Several such advances are discussed here.

New image analysis methods using Magnetic Resonance Imaging (MRI) can provide measures of brain shrinkage globally and in different regions of the brain. Computer programs can allow serial analyses providing a measure of brain changes over time in research studies. New MRI techniques such as Magnetic Resonance Spectroscopy may allow determination of changes in brain chemicals in research studies.

Imaging technologies using Positron Emission Tomography (PET) are providing better diagnostic tools. Modern "molecular imaging" using radiopharmaceuticals that bind to beta-amyloid protein or tau protein, are able to visualize, using PET, deposits of these abnormal brain proteins in the brains of living individuals. Now available both commercially and for research are three different PET amyloid-imaging agents (florbetapir, florbetaben, and flutemetamol), and additional amyloid-imaging agents are under testing — as well as agents that are believed to image abnormal tau deposits. These techniques potentially can substitute for more invasive procedures such as brain biopsy. Accuracy of diagnosis is much improved by having information as to whether Alzheimer's pathology is or is not present in a person affected with cognitive impairment. In addition to providing better diagnostic information, following PET molecular images may provide information as to progression or regression of Alzheimer's changes in the brains of research participants.

Biochemical techniques now allow for exquisitely sensitive analysis of proteins in blood or cerebrospinal fluid. Using these measures provides greater diagnostic certainty, much like molecular imaging. These measures also have the potential to allow for "molecular markers" of progression of the disease. These markers allow researchers to determine small changes in brain biochemistry that may not be evident on questionnaires or pen and paper testing. These biochemical tests hold the promise of allowing research answers to be obtained in studies of shorter duration and few participants, accelerating the pace of research.

Technological advances in the laboratory may also provide additional treatment possibilities. It is now possible to isolate from blood or a small skin biopsy "stem cells" that can differentiate into nerve cells in a dish. These cells hold the promise of possibly allowing replacement of cells lost to degeneration.



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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:

May 20	5:30 – 7:30 p.m.	Manhattan
May 20	6:00 – 8:00 p.m.	Brooklyn
May 27	6:00 – 8:00 p.m.	Upper Manhattan

June 4	12:30 – 2:30 p.m.	Queens
June 9	5:30 – 7:30 p.m.	Manhattan
June 12	Noon – 2:00 p.m.	Manhattan
June 17	1:00 – 3:00 p.m.	Brooklyn
June 17	5:30 – 7:30 p.m.	Manhattan

July 2	12:30 – 2:30 p.m.	Queens
July 10	Noon – 2:00 p.m.	Manhattan
July 14	5:30 – 7:30 p.m.	Manhattan
July 15	5:30 – 7:30 p.m.	Manhattan
July 15	6:00 – 8:00 p.m.	Brooklyn

August 6	12:30 – 2:30 p.m.	Queens
August 11	5:30 – 7:30 p.m.	Manhattan
August 14	Noon – 2:00 p.m.	Manhattan

Upcoming Dates Just for Professionals:

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

August 12	6:00 – 8:00 p.m.	Upper 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:

June 4	5:30 – 7:00 p.m.	Manhattan
July 9	5:30 – 7:00 p.m.	Manhattan
August 6	5:30 – 7:00 p.m.	Manhattan

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

Registration is required. Space is limited.

Placing Your Relative in a Nursing Home

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

Upcoming Dates:

June 16	5:30 – 7:00 p.m.	Manhattan
July 21	5:30 – 7:00 p.m.	Manhattan
August 18	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:

May 18	5:30 – 7:00 p.m.	Manhattan
May 28	5:30 – 7:00 p.m.	Manhattan
June 1	Noon – 1:30 p.m.	Manhattan
June 15	5:30 – 7:00 p.m.	Manhattan
June 25	5:30 – 7:00 p.m.	Manhattan
July 6	Noon – 1:30 p.m.	Manhattan
July 20	5:30 – 7:00 p.m.	Manhattan
July 23	5:30 – 7:00 p.m.	Manhattan
August 3	Noon – 1:30 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.):

June 15

The Moral Challenges of Alzheimer’s Disease: Ethical Issues from Diagnosis to Dying

- What are the ethical issues faced by family members of persons with dementia?
- How can we address these issues?

Speaker: Stephen G. Post

July 13

Using Personalized Music to Improve Quality of Life

- Why personalized music? What is the science and benefits behind it?
- How to create a personalized playlist and gain support of a nursing home or assisted living facility.

Speaker: Dan Cohen

August 10

Family Conflicts in Caregiving

- Recognizing different styles of communication
- Understanding the role of mediation services and setting appropriate boundaries

Speaker: Ana Araujo

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

Upcoming Events

May 18

We Sing & Dance

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

June 2&11

Mind & Body

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

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:

June 2, 9, 16, 23 – Manhattan
 Noon - 2:30 p.m.

July 7, 14, 21, 28 – Manhattan
 Noon - 2:30 p.m. (Spouses only)

July 8, 15, 22 & 29 – Manhattan
 5:30 p.m. – 8:00 p.m.

August 5, 12, 19, 26 – Manhattan
 Noon - 2:30 p.m.

August 6, 13, 20, 27 – Manhattan
 5:30 p.m. – 8:00 p.m.

Upcoming Series Dates in Spanish:
 May 22, 29 & June 5, 12 – Brooklyn
 1:00 p.m. – 3:30 p.m.

Attendance is required at all workshops in a series.



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