



caringkind

The Heart of Alzheimer's Caregiving

FORMERLY KNOWN AS THE ALZHEIMER'S ASSOCIATION, NYC CHAPTER

SPRING 2016

- The NYC Chapter of the Alzheimer's Association breaks away from National as CaringKind on page 6.
- Please support our Spring Campaign on page 17.

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www.caringkindnyc.org
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Dear Friends,

In December, when we broke away from the National Alzheimer's Association to return to our roots as an independent charity, we knew we would need a new name that exemplified the very core of who we were: an organization with more than three decades of experience developing and implementing innovative, creative, and leading-edge caregiving initiatives.

So, we stepped back and assessed what we did best. And what we do best – where we have always excelled – is understanding the needs of New York City caregivers and providing them with the support they need to care with confidence today and, just as important, to plan for tomorrow.

We then asked ourselves, “What kind of person does it take to be a caregiver for someone who has Alzheimer’s or dementia?”

The answer was very clear. It takes a special kind of person to rise to the challenge. It takes the courageous kind. The listening kind. The loving kind. It takes the caring kind.

As soon as we said this, we knew we had it. Choosing a meaningful name for our organization – one that would resonate with New York’s dementia caregiving community – was really as simple as this:

CaringKind

The Heart of Alzheimer's Caregiving.

At CaringKind, we see people, not a disease. We understand that one caregiver’s experience is not like any other. And we help individuals

and families affected by a dementia diagnosis to find the right path to best meet their unique needs. From that first call to our 24-hour Helpline, our trained professionals offer the guidance caregivers need, when they need it, to make each day a little bit brighter.

At CaringKind, we know there is no one-size-fits-all approach to dementia caregiving. Our Education and Training programs and Social Work Services help ease the emotional, physical, psychological, and financial burdens of managing the disease, while we treat each individual and family with dignity and compassion. Our support groups are a lifeline for caregivers.

And, in continuing our deep commitment to provide care and support to people who are living with Alzheimer’s and dementia, we are also helping improve the quality of life for the caregiver. For instance, our state-of-the-art Harry and Jeanette Weinberg Early Stage Center will continue to provide a safe, supportive environment and specialized programs for a growing number of people. And thanks to CaringKind’s strong relationship with the NYPD, our Wanderer’s Safety Program will continue to provide resources to protect those who wander.



LOU-ELLEN BARKAN

President & CEO

lbarkan@caringkindnyc.org

Today we can say with pride that CaringKind is a strong community of people, not just a network of resources. We have unparalleled and deep local roots in the complex, bustling city we call home. Our partnerships with nursing homes, major medical centers, and world-renowned researchers are stronger than ever.

At CaringKind, with your help, we will create a world where the stigma of an Alzheimer’s or dementia diagnosis no longer forces families to retreat, but helps them to reach out and ask for help.

I am proud of what we have accomplished and grateful for the years of your support that have made us who we are today: CaringKind, The Heart of Alzheimer’s Caregiving.

Sincerely,

Dear Readers,

Welcome to a new chapter in our history. Welcome to CaringKind. As you probably know, after careful consideration, our Board of Directors has decided to disaffiliate from the National Alzheimer's Association and return to our roots as an independent 501(c)(3).

Please know that we remain deeply committed to providing quality care and support services to all New Yorkers who need them, as we always have. To the credit of our Board of Directors, outstanding staff, and senior management team, if you visit any day you will see business as usual:

The 24-hour Helpline staff busily answering calls, providing information, education, and a connection to our rich portfolio of services and community partners, thereby providing desperately needed connections and comfort.

Support groups meeting in the support group rooms, the members finding much needed solace and support.

Family Caregiver Workshops and Dementia Care Trainings for Professionals taking place, where caregivers are learning the fine art and skill of good dementia care.

Education programs being held, helping families negotiate the complex system of long-term care, including seminars on legal and financial planning, Medicaid home care, and placing a relative in a nursing home.

The Harry and Jeanette Weinberg Early Stage Center bustling with new programs, as well as loads of laughter and friendship.

Social workers counseling families, providing personalized guidance to those in need who are often not only

struggling with providing care for their relative, but also with difficult issues including poverty, food insecurity, looming homelessness, immigration status, drug and alcohol use, chronic illness of their own, longstanding mental health issues, and family conflict.

Our Diversity team reaching out to community centers, faith-based communities and more, bringing our message of hope and awareness to every corner of the city in English, Spanish, Cantonese, and Mandarin.

Our Medical & Healthcare Professional Outreach Manager working with doctors, nurses, social workers and others in medical practices, hospitals, and pharmacies across the five boroughs to educate them about our resources.

Our Residential Care Policy & Strategy Consultant bringing the hope of superb care and comfort for those in residential settings and beyond, informing the palliative care world about the importance of looking at palliation through the dementia lens.

Our Wanderer's Safety Program team enrolling persons with dementia in the jewelry identification program or responding to reports of missing individuals with memory loss with our partners at the NYPD, the Office of Emergency Management, and the city's Department for the Aging, providing support to families dealing with the nightmare of a missing person with dementia.



JED A. LEVINE

Executive Vice President, Director of
Programs & Services
jlevine@caringkindnyc.org

Thanks to a generous grant from the New York State Department of Health, we are working more formally with the vast array of cultural and arts institutions in the city, helping to make them dementia-capable. We are starting new partnerships with the Lincoln Center for the Performing Arts, the Queens Museum, and the Cloisters. This grant, an expansion of the AlzCAP contract, is allowing us to extend our services in many other ways as well. (More about that in my next column!)

We are still deeply committed to supporting research, sharing information about the latest research developments and helping you locate research trials.

Our new name says it all – we are the heart of Alzheimer's and dementia caregiving and remain committed to providing the personal support that all caregivers need and deserve. We will continue to individually guide each caller and client to help make what is often the darkest hour a little bit brighter. We are New Yorkers serving those who live and work in our great city. If you need our help we are only a phone call away at 646-744-2900, 24 hours a day.

New York City Chapter of the Alzheimer's Association Breaks Away from National to Return to our Roots as an Independent, Stand-Alone Charity Called CaringKind, The Heart of Alzheimer's Caregiving

On December 1, the New York City Chapter of the Alzheimer's Association announced our separation from the National Alzheimer's Association, based in Chicago, to return to our roots as a stand-alone, independent charity. The nation's leading experts in Alzheimer's care, education and support can still be found at 360 Lexington Avenue under the new name, CaringKind, The Heart of Alzheimer's Caregiving.

CaringKind will continue providing compassionate care and life-saving support in New York City for the hundreds of thousands of families and individuals affected by Alzheimer's and related dementias as we have done for more than 30 years.

The disaffiliation came after the National Alzheimer's Association made the decision to restructure the organization in a plan they called "Mission Forward," combining all of its local chapters into one single 501(c)(3) organization – in essence, a single charity.

This significant structural change would have severely affected our ability to provide the same quality and level of service which has benefitted New Yorkers for over three decades. Decisions about the vital programs would have been turned over to individuals hundreds of miles away in Chicago. Consolidating into one central charity would have meant losing control over management and the dissolution of our dedicated and generous governing Board of Directors.

Operating as an independent charity will create numerous economic and fundraising opportunities for CaringKind. We will now be able to keep 100% of every dollar raised to support all of our free

programs and services (under the National Association's shared fundraising system, 40% of every unrestricted dollar we raised went to National). Now, CaringKind will have the freedom to partner with major corporations and funders. We'll be able to initiate cause-marketing programs and give funders the opportunity to brand materials, programs, and events.

Lou-Ellen Barkan, our President & CEO, said, "I want to assure New York City's Alzheimer's community and all of our clients, partners, supporters and friends that nothing has changed except our name. There will be no disruption of service. It will be business as usual at 360 Lexington Avenue. We will remain the premiere organization in New York City singularly focused on care and support for individuals with Alzheimer's and related dementias and their families." Lou-Ellen added that New Yorkers will be able to rely on the same high quality service they have come to expect for more than 30 years:

- Hundreds of free support groups, workshops, and educational seminars for caregivers and people with the disease will continue.
- Satellite programs in Queens and Brooklyn will stay as busy as ever.
- The state-of-the-art Early Stage Center will remain open for business.
- Outreach efforts to the African American, Latino, Orthodox Jewish, Russian, Chinese and LGBT communities will continue.

- Dementia care training programs for home health aides and other health care professionals will proceed uninterrupted.
- Partnerships with nursing homes, major medical centers, world-renowned researchers, and the entire Alzheimer's community in New York City will grow stronger than ever.
- Thanks to CaringKind's intimate and strong relationship with the NYPD, we will still offer a resource to protect New Yorkers with dementia who wander.
- The 24-hour Helpline will continue to be the best way for New Yorkers to access expert and caring advice 365 days a year. The new Helpline telephone number is 646-744-2900.

For more than 30 years, the Alzheimer's professionals who work at 360 Lexington Avenue have served hundreds of thousands of clients from New York City, including individuals with dementia and their families, and the professionals who provide their care. Our organization has been a consistent and strong presence in the NYC community.

Lou-Ellen concluded, "This organization is the nation's model for innovative, creative and leading-edge caregiving. We are dedicated to delivering human-centered care to the heart of our diverse New York communities. We help caregivers and people living with dementia have full and meaningful lives. And, in the absence of effective therapies and a cure, the best therapy – the only therapy – is good care...and this is where we excel."

On Tuesday, March 1, and Wednesday, March 2, we were delighted to host more than 250 Board members, friends, supporters, celebrities, the NYPD, and community and research partners as we revealed our new public name, brand, and vision for the future of caregiving in NYC. We were proud to introduce *CaringKind, The Heart of Alzheimer's Caregiving* and we were especially gratified by the outpouring of support and endorsement for our transition back to an independent New York City charity.



President & CEO Lou-Ellen Barkan takes to the podium to announce CaringKind, The Heart of Alzheimer's Caregiving



From Left: Board members Sharon Kilmer, Lori Oscher Friedman and Marilyn Cohen



Executive Vice President Jed A. Levine addresses the attendees



More than 250 people joined us for our two-night CaringKind launch celebration



From Left: Jed Levine and Lou-Ellen Barkan are joined by actor and Alzheimer's advocate David Hyde Pierce



From Left: Lou-Ellen Barkan was presented with flowers from Dave Duplay and Courtland Long, both of healtheo360



From Left: Board member Jon Henes, Carol Berne, Dr. Peter Davies and Lou-Ellen Barkan



From Left: New York Alzheimer's research partners with Lou-Ellen Barkan and Jed Levine



Board Co-Chair John Latham welcomes guests to the launch event



From Left: David Hyde Pierce, Jed Levine, David Rottkamp, Board Co-Chair Stephen Casper and Lou-Ellen Barkan



From Left: Lou-Ellen Barkan, Jed Levine, Department for the Aging Commissioner Donna Corrado and Dr. Max Gomez



From left: Junior Committee President Laurel Crosby, Junior Committee Secretary Maxine Squires, Board member Mike Schnitzer, Junior Committee Vice President Brittany Krygowski and Junior Committee Treasurer JC Hay



From Left: Board Co-Chair Benjamin Jenkins, Lou-Ellen Barkan, Jed Levine and Dr. Mary Sano



Longtime supporters of our annual Walks celebrated the CaringKind launch with our staff



Board members Nathan Halegua (left) and Jeffrey Jones (right) with Ken Berger

The decision to separate from National and return to our roots as a stand-alone, independent charity was a momentous event in our 30-year history. It was also a big newsmaker.

As the first Chapter (of now six) to announce disaffiliation from the Chicago-based National organization, we were the subject of an exclusive *Wall Street Journal* story that explained in detail the important programmatic and financial reasons for the split. The article read, in part, “Leaders of the New York City Chapter say the consolidation plan would have dissolved the local board, taken the organization’s assets and jeopardized programming that supports caregivers and individuals suffering from Alzheimer’s.” Stephen Casper, Co-Chair of our Board of Directors, told the *Journal* that “operating as a separate organization was in the best interest of local clients who desperately need our help.”

Significant stories about our becoming independent and our new brand also appeared in other respected publications, including *The Chronicle of Philanthropy*, *The Huffington Post*, *New York Nonprofit Review*, *The NonProfit Times*, *Philanthropy News Digest*, *Alzheimer’s News Today*, on Alzheimer’s Reading Room and elsewhere.

On March 6, the entire nation, including all of us here at CaringKind, mourned the passing of Nancy Reagan. As Jed Levine wrote in *The New York Times*, “Nancy Reagan played many roles throughout her long and storied life... perhaps none more inspiring than her role as Alzheimer’s caregiver for her beloved Ronnie. Her openness and bravery in the face of this devastating disease was a model for many others,

opening doors to discussion and reducing the stigma of Alzheimer’s.” Lou-Ellen Barkan expressed similar sentiments in a moving TV interview with PIX 11, in which she also noted the sea change in public opinion about Alzheimer’s after President Reagan disclosed that he had the disease.

Lou-Ellen continues to blog for *The Huffington Post*. In a recent post, “Absent Effective Treatments, Good Care is the Best Medicine for Alzheimer’s,” she stressed the importance of the work we do at CaringKind, saying, “The care we provide improves the daily lives of those navigating the challenges of an Alzheimer’s or dementia diagnosis and lets New Yorkers know they don’t have to do it alone.”

News of a brand-new partnership between CaringKind and *healtheo360* – a web portal for patients and caregivers seeking support and information about chronic health conditions – was reported on more than 200 news websites around the country. This initiative will provide a virtual support group for the more than 250,000 New York City residents affected by a diagnosis of Alzheimer’s or a related dementia and their families.

We were also proud to be part of a recent public radio series called “Strike a Chord: Family Caregivers.” Matt Kudish, Senior Vice President of Caregiver Services, and caregivers Sharon Corso and Keith Amparado participated in a 30-minute panel moderated by George Bodarky, WFUV

news director. The segment highlighted the realities of what it means to be an Alzheimer’s caregiver and ways our dedicated staff can help ease the burden.

Our annual Walks, which took place in Manhattan, Brooklyn, Queens and – for the first time ever – Staten Island, were huge successes. Television coverage was extensive and featured interviews with Lou-Ellen, actor and longtime CaringKind supporter David Hyde Pierce, and NYPD Officer Richard Fazio, who was honored for his work with our Wanderer’s Safety Program. The *Staten Island Advance* profiled 23-year-old Alexandra Gardiner, our volunteer chairperson for Staten Island’s first walk. Alexandra supports CaringKind in honor of her grandfather, who had Alzheimer’s and died three years ago. She said that, although she can no longer help her grandfather, she is happy that she is able to help others.

Like Alexandra, if you have a story about a special personal experience with us that you’d like to share with the media, please email Danielle Robitaille, Vice President of Marketing & Communications, at drobitaille@caringkindnyc.org. She’d be happy to talk with you about it.

We have an exciting year ahead of us! Look for us in the news!

“ I recently read about your name change and disaffiliation from the National Alzheimer's Association. I am a bit concerned and hope you can explain how this will affect those of us who depend on your organization for assistance and education. I attend a support group at the office at 360 Lexington Avenue, which I find extremely helpful. Will you be moving your office or changing your programs?”



STEPHANIE ARAGON
Director of Helpline
helpline@caringkindnyc.org

Rest assured that only our name has changed. Our mission to focus on care and support for individuals with Alzheimer's disease and related dementias and their families will never change. You can still reach us 24 hours a day, 365 days a year in 200 languages. Our new Helpline number is: **646-744-2900**. This is the only number you need to connect with New York City's dementia experts. Our Helpline Specialists can provide you with the most up-to-date information, education, and support. We're here for you. All of our programs and services will continue without interruption!

We continue to offer the Understanding Dementia Seminar, our introductory seminar that provides information about Alzheimer's disease and other types of dementia, several times a month throughout each of the five boroughs in NYC. During this seminar, caregivers also learn about what resources and services are available to help them cope with present challenges and future planning.

Our Legal & Financial Planning Seminar, which is conducted by an elder law attorney multiple times a month, continues to give caregivers information about the durable power of attorney, living will, and health

care proxy, as well as introductory information about Medicaid coverage.

Our Medicaid Home Care Seminar is still held once a month, led by an attorney who provides information for caregivers to be better able to complete the application and move through the process independently.

Call our 24-hour Helpline to ask what new topic we are discussing at our Monthly Educational Meeting, held on the second Monday evening of every month, as the topic varies from month to month.

Our Dementia Care Trainers are actively recruiting participants for both family and professional trainings. Our Family Caregiver Workshop is a ten-hour series that focuses on a person-centered care approach designed to improve the quality of life for both the caregiver and the person with dementia in a supportive and nonjudgmental environment. This training is offered at a variety of times in order to accommodate the diverse schedules of caregivers throughout the city. There is also availability for our nationally recognized Dementia Care Training for Professional Caregivers. Through this professional training, we continue to empower direct care workers to provide the highest quality of care to persons with dementia.

We also offer the Moving Your Relative to a Nursing Home Seminar once a month, providing an overview on long-term care options and the steps involved in moving a person with dementia to a nursing home.

To register for any of the our free programs or to receive more information about the services we offer, please feel free to call our 24-hour Helpline at 646-744-2900.

You can also call us for emotional support as often as you need. We know that living with Alzheimer's can be overwhelming at times. Remember, we are here for you – all day, every day.

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

646-744-2900

Social Work Services



ANNE M. FOERG
Director of Social Work
afoerg@caringkindnyc.org

Confusing, complicated, exhausting, infuriating, isolating, and life-changing – just a few of the words that describe the experience of suffering from dementia, as well as the experience of caring for a person with the condition. Despite the commonalities, each individual's experience is unique, with the potential to be as varied as the lives of each person who comprises the mélange that is New York City's eight-plus million residents. So what do you do when...

- Your wife has just been diagnosed with Alzheimer's disease, and you both are struggling to understand and cope with what this means?
- Your dad, who has dementia, is having increasing difficulty with tasks like taking medication, going shopping, and managing doctor's appointments? You want to support his independence, but it is clear that he needs more assistance than you can provide.
- You suspect that your neighbor may be suffering from dementia because she seems increasingly confused, often walking outside in her bathrobe or asking you for help with simple tasks like mailing a letter? What can you do?
- Your husband has been diagnosed with frontotemporal degeneration and you have young children who do not understand what is happening to their father?
- Your grandfather has been diagnosed with Lewy body dementia and continues to drive, despite having caused several accidents?
- You provide around-the-clock care for your husband with Alzheimer's disease and you rarely have a break? The stress is beginning to impact your emotional and physical wellbeing, but you do not have any time to take care of yourself.
- Your mother has been living alone in her native country when you become aware that she is experiencing problems with her memory and thinking that are jeopardizing her safety? You suspect that she has dementia and your only option is to bring her to live with you in the United States, but wonder if there are medical services and social supports available to a non-citizen.
- Your adult son with dementia has started to wander out of the house and, despite your best efforts, he manages to get out while you are in the bathroom or sleeping? How do you keep him safe while ensuring that you have time to take care of your needs?
- You are beginning to understand that it is no longer safe for your sister with vascular dementia to live alone? Is it feasible for her

Caring for a person with dementia cannot be done alone; it requires a system of support.

to remain at home with care or should you consider moving her to residential facility?

- Your family is struggling to care for your aunt with dementia, but no one can agree on what should be done? She has no legally-designated proxies, and each family member has a different opinion about what she needs, how her money should be spent, and who should be making these decisions.

The answers to these questions are not simple, and we cannot pretend that they are. This is why the Social Work Services team at CaringKind is best situated to help you navigate the emotional and the practical impact of dementia, because it is impossible to divorce the two. Our trained professionals provide individualized, in-depth guidance to help negotiate the challenges of living with and/or caring for someone with dementia. We counsel individuals and families by assisting in creating a plan of care, navigating the varied systems with which they come into contact, and developing strategies to manage the communication, behavior, and medical challenges they face.

Equally important, we work to support caregivers in caring for themselves, providing guidance to ensure that they have the physical, emotional, and financial capacity to continue their important work. Caring for a person with dementia cannot be done alone; it requires a system of support, and our Social Work Services team welcomes the opportunity to become part of your team. To be connected with one of our professionals, please call the 24-hour Helpline at 646-744-2900. Appointments are available in-person at our main Manhattan office or our satellite offices in Brooklyn and Queens, as well as by telephone or via email. In the course of your unique journey, there is never a wrong time to reach out.

A Caregiver's Journey

By Suzanne Campbell

It is commonly said that Alzheimer's disease affects different people differently; so if you know one person with Alzheimer's, you know just one person with Alzheimer's disease. Based on my own experience as a caregiver, I can attest to the accuracy of this statement. Sadly, the truth of it only adds to the complexity of living with this disease. While there are certainly some manifestations of the disease that are similar, each individual's specific course and progression is unique. The same is true for the caregiver's journey. As caregivers, we live through the loss of someone. The specifics of our individual experiences of loss are also unique to the relationship, to who we are as individuals, and to the course and duration of the disease. It is through understanding the commonality of the individual experiences of loss and living with this disease that I have found participating in an Alzheimer's caregivers support group at CaringKind so powerful. While the specifics of our situation are unique, we are not alone.

My journey as a caregiver began almost 11 years ago. In thinking about my experience, the opening sentence from Charles Dickens' *A Tale of Two Cities* seems so appropriate: "It was the best of times, it was the worst of times, it was the age of wisdom, it was the age of foolishness, it was the epoch of belief, it was the epoch of incredulity, it was the season of Light, it was the season of Darkness, it was the spring of hope, it was the winter of despair, we had everything before us..." My husband Bill was diagnosed with Alzheimer's just months after our first wedding anniversary. I still say he is the best

thing that ever happened to me. We felt so lucky to have found each other and were looking forward to building our life together. When Bill was diagnosed, at first we were in denial, then devastated, and finally sank into deep sadness with the realization of what this meant for Bill, our future, and our life together.

Looking back with the inside knowledge of this disease that I have now, I can see signs of how it was already impacting my husband before we got married that I didn't recognize as symptoms at the time. It was Bill's boss who ultimately raised the flag and said something was really wrong. By the end of our first year of marriage, Bill had to retire on disability, and I have continued to work full time. While the disease started off insidiously, the progression became more and more challenging for both of us. I have found that each stage is difficult in different ways. This early phase was so hard for Bill as he experienced each painful loss of his mental abilities, and it was hard for me because his behavior changed. He became more angry and hostile, different from the man I married. I too was angry at what this disease was doing to him, to us, and to my life.

Trying to hold it all together for both of us was very stressful, and after a few years it was becoming almost impossible. This time it was my boss who knew something was wrong, and he encouraged me to get help. A friend of mine whose mother had Alzheimer's suggested I contact CaringKind about joining a support group. I called the Helpline, and shortly thereafter met with Sharon Shaw for an interview to join a spouse's support group. Joining this group has been essential to my survival! I admit that it was frightening at first, as several of the spouses in the group were caring for partners who were much further along in the progression of the disease than Bill. It was terrifying to think that this was where we were heading.

But, forewarned is forearmed! The group experience has been so important to me for many reasons. Most importantly, it was the only time during the week that I took for myself. It has been the only place where I could share the anger and sadness that I have felt, and where others could relate to my feelings or at least understand them. At times I have been silent, or cried through the session without sharing. It's an hour and a half each week when I don't have to hold it all together. It's a place where I have gotten great practical advice about supplies and approaches to help manage caring for Bill. And it's a place where I am reminded and encouraged to think about and to take care of myself – something I haven't been very good at. I feel a very strong bond with my fellow group members.

Once connected with CaringKind, I also took advantage of several of its education meetings and workshops including the Family Caregiver Workshop and the Legal & Financial Planning Seminar. These sessions provided important tips and information that would help me plan for my own future. I learned how critical it is to start planning and take action as early as possible when considering the potential long-term financial consequences of this disease. I found it overwhelming both emotionally and practically to really come to terms with the steps I needed to take to ensure my husband's continuing care and to protect my own financial future. Attending these workshops as soon as possible after receiving an Alzheimer's or dementia diagnosis is key to being able to plan and take action. I wish I had started sooner.

Five years ago, my mom was also diagnosed with Alzheimer's. There had been unmistakable signs for a few years leading up to her diagnosis. The year that she died was probably the most stressful year of my life. Her anxiety and paranoia seemed to peak around the same time as Bill's personality changed. I would

get phone calls at work from my mom begging me to come home because she believed she was being held at knifepoint, and calls from Bill's caregivers that he wouldn't let them into the apartment or that he had run them out of it. And as fate would have it, my challenges at work peaked at the same time. Fortunately, I was not the sole caregiver for my mom as I've essentially been for my husband. I have three siblings who were all willing to help, one of whom in the primary caregiver role. I shared my support group experience with them, recognizing that they could benefit from my participation even if they didn't join a group themselves. My mom passed away two years later, mercifully, in my opinion, as she did not have to linger through years of slow deterioration. At this time, Bill had reached a point where he could no longer be my partner; I more strongly felt the loss of him as my partner as I grieved losing my mom. My life was so hectic that I was unable

to attend the support group regularly, and I came to realize how important it had become in my ability to cope.

About a year later, Bill's physical health declined sharply. No longer able to walk or care for himself at all, he entered a home hospice program and has needed 24/7 care at home for almost two years. I continue to work full time and my participation in the support group remains key to my survival. In July 2014, we transitioned into a new phase as I placed Bill in a care facility. It was a move I'd dreaded and hoped we wouldn't have to make, but it became financially untenable to continue the care at home. It was a difficult change to make, but now that I'm on the other side of it, I can see that everything is going to be OK.

I'm now figuring out how to manage through this phase of loss and caregiving as my journey is not yet over. As part of this process, I stepped up to be an

advocate. For me, it's an important way to give back to CaringKind for the critical role the organization and my support group have played in my journey. It's also a way to continue Bill's and my mom's fight against this monster of a disease. As grateful as I am for my support group, I hope that one day Alzheimer's support groups won't be necessary. I hope that this disease won't continue to steal our loved ones' personhoods, or exact stressful tolls on their caregivers. Until there is a treatment to prevent the onset of Alzheimer's, it's important to me to raise awareness about the personal and financial impact of the disease, as well as the amazing and critical support that CaringKind provides.

Bill Campbell passed away shortly after this article was written. Our condolences to Suzanne, who remains involved in the mission of CaringKind.

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ABIGAIL NATHANSON
Director of Support Groups
anathanson@caringkindnyc.org

Our New Director of Support Groups

I got to know the people and programs of CaringKind almost a decade ago, when, as a recent graduate of the NYU School of Social Work, I attended a conference here on best practices in dementia care. The wealth of knowledge and services available for caregivers and professionals amazed me, so I volunteered to be a support group leader. My group ran for two years during which I worked on the dementia unit of a nursing home until I left and went on to work in hospitals, hospice, research, and outpatient mental health, as well as teach in a graduate program.

Wendy Panken, the former Support Group Manager, and I reconnected early last year, and she mentioned there was a long-standing group looking for a new leader. I was excited to get involved again, and was reminded of the great work being done every day. When Wendy retired later in the year, I stepped into the Director of Support Groups role at CaringKind in October. What started as a personally enriching volunteer gig has turned into a new career, doing what I love with an organization that is so important to me. Support groups save lives, and I am profoundly grateful for the 80-plus people all over New York City who give their time every week to our organization and to the dementia community by running groups.

Moving forward, the program will continue to focus on high-quality care, expand into more underserved areas, and provide more opportunities for support group leaders to connect with CaringKind. My role is to develop and manage the program to best meet the needs of our caregivers, support group leaders, and organization. We have already made massive improvements to our referral and screening process, and look forward to unveiling new projects and services that assist caregivers and our support group leaders in the coming year!



WEIJING SHI
Manager of Chinese Outreach
wshi@caringkindnyc.org

Our New Manager of Chinese Outreach

I first was introduced to CaringKind by Fanny Lau, former Manager of Chinese Outreach. Fanny and I had several opportunities over many years to work together serving the Chinese community. Through our collaborations, I gained an overall knowledge of Alzheimer's disease and related dementias and became familiar and impressed with the programs and services provided by CaringKind. Now that Fanny has retired, I am confident that I will build on the strong foundation she created to reach more families with our message of hope and help.

I earned a college degree in Chinese Language & Literature in China and a Masters of Social Work from NYU. I

worked in Chinese senior services as a clinical social worker for several years, learning to better work with older adults. I was the Brooklyn branch director of Chinese American Planning Council for several years, where I truly witnessed the cultural influences on aging and the barriers to accessing social services. I then worked at NYU Lutheran Health System as a Chinese community liaison. I have had many opportunities to learn and improve my outreach and education skills, as well as build a substantial network of colleagues and partners within the Chinese community. I have approached all my previous positions as learning and networking opportunities, and believe I have earned a good reputation. I am very excited about this new phase of my career.

After years of hard work, education, outreach, and advocacy from CaringKind there has been a growth in the awareness and understanding of dementia in the Chinese community. However, there is still much work to be done. Many Chinese people who are dealing with dementia are reluctant to ask for help. There is insufficient information about how to access community resources. Many Chinese caregivers who lack such care and support experience a variety of emotional and psychological issues and family conflict. I will continue to deliver our mission and introduce services to the community by promoting our unique approach to care for Chinese people with dementia. I will also provide support for both family and professional caregivers, educate Chinese residents about dementia, and enhance our partnerships with community health care and social services agencies. My goal is to build a bridge between CaringKind and the Chinese community!

Palliative Care for People with Dementia



ANN WYATT

Residential Care Policy and
Strategy Consultant

awyatt@caringkindnyc.org

Since 2012, CaringKind has been working with three New York City nursing homes to implement a model of palliative care developed by the Beatitudes Campus in Phoenix, Arizona for people with dementia. Based on our continuing work with Beatitudes and three homes, Cobble Hill Health Center in Brooklyn, and Isabella Geriatric Center and The New Jewish Home in Manhattan, we have developed guidelines for long-term care facilities to assist in the implementation of best practices in palliative care for people with dementia. This document, *Palliative Care for People with Dementia: Why Comfort Matters in Long-Term Care*, will be available on our website within the next few weeks, and copies will also be distributed to nursing homes throughout New York State as well as to other community partners across the country.

75% of people with Alzheimer's or related dementias will spend time in a nursing home.

Seventy-five percent of people with Alzheimer's or related dementias will spend time in a nursing home, most typically in the moderate and advanced stages. Alzheimer's is a progressive, terminal disease; the average time between diagnosis and death is eight to ten years. But it is extremely variable and can last up to 20 years or more. Generally, about 40% of this time is spent in the advanced stages. For these reasons, it is crucial that long-term care providers bring palliative care to their residents who have dementia, and by extension to their families and friends. Palliative care has a great deal to offer the person with dementia, and it is important to understand that this does not mean giving up. It means taking active steps to discover what comforts someone and even gives them pleasure, and taking steps to prevent or avoid unnecessary pain and suffering before they take hold. The more advanced the dementia, the more helpful palliative care can be, which is why it is so essential that nursing homes adopt a palliative approach.

Sadly, palliation isn't usually considered often for people with dementia. And even if it is, unless modifications are made in how palliation is offered and delivered, it is unlikely to be effective. As an individual's dementia advances, his or her actions, rather than words, most likely communicate distress. Unfortunately and all too often, these behavioral expressions are not understood as distress, but rather they are assumed to be the inevitable consequences of the dementia's progression. Palliation cannot occur if the reason or triggers for distress are not known or understood. Anti-



The Palliative Care for People with Dementia cover

psychotic, anti-anxiety and sedative medications do not take away pain or distress, nor do they comfort someone living with dementia who may be hungry, cold, hot, tired, lonely, or frightened by noises or activity in the environment. Effective palliation for people with dementia includes more accurate pain identification and management, liberalized diets, and flexibility in wake/sleep times as well as all other daily routines.

Our experience over the last few years working with our three partner nursing homes and Beatitudes has clearly demonstrated that when palliative care is appropriately adapted to the needs of people with dementia, there is enormous benefit – to the person with dementia, to their families and friends, and to facility staff.



CAROL BERNE

Senior Vice President of Development
cberne@caringkindnyc.org

As you have read throughout this newsletter, we have launched! Our new public name, CaringKind, The Heart of Alzheimer's Caregiving, reflects the important role that we play in the lives of caregivers and persons with dementia, coupled with the more than 30 years of expertise in the field of dementia care.

How has the philanthropic community responded to our independence? I can say with great pride that we have received resounding support and endorsement from individuals, foundations, and corporations. A perfect example is our Year-End Campaign, which achieved a record-breaking **\$1 million**, surpassing last year's total by 66%. Over 1,030 individuals, many of whom are our clients, with gifts large and small showed their support by either making a first-time gift or significantly increasing their prior level of support. Our donors have particularly appreciated that 100% of their donation now stays in New York City, supporting our local community. We thank you.

As more and more individuals and families are affected by a diagnosis of Alzheimer's or a related dementia, the need for our services will only grow. We remain the only organization in NYC

singularly focused on dementia care and support. During this time of transition, as we build awareness for CaringKind, we ask you to continue to lend support – become a CaringKind Founder, annual donor, supporter of our annual Walk, corporate partner, or a participant in an Athletes to End Alzheimer's (ATEA) event. Our caregiver programs and services are free of charge because of you.

It is also particularly important for you to “know your charity,” and who you are supporting. Please see below and page 18 for more information.

We are now starting our Spring Mother's Day and Father's Day Campaign, a special time to recognize and honor a loved one or someone dear to you. Please see this year's poignant letter written by Laurel Crosby, President of our Junior Committee, on the following page. Thank you again for your commitment to our work. Please contact me directly if you wish to make a gift or have any questions.

Our Year-End Campaign achieved a record-breaking \$1 million.

CaringKind 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.



CaringKind meets the Better Business Bureau Wise Giving Alliance Standards for Charity Accountability.

Know Your Charity

The following organizations ARE NOT affiliated with CaringKind:

- Alzheimer's Association
- Alzheimer's Association, New York City Chapter
- Alzheimer's Disease Resource Center (ADRC)
- Alzheimer's Drug Discovery Foundation
- Alzheimer's Foundation of America (AFA)
- Bright Focus Foundation
- Long Island Alzheimer's Foundation (LIAF)
- Staten Island Alzheimer's Foundation (SIAF)

Ways to Give

Giving by Check

Please make checks payable to CaringKind. For your convenience, a self-addressed postage paid envelope has been provided in this newsletter.

Online/Credit Card

Visit www.caringkindnyc.org and click on Ways to Give 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. Please speak to your tax advisor.

Bequests

By remembering CaringKind 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 CaringKind (or Alzheimer's Disease and Related Disorders, New York City, Inc.) 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 CaringKind program).

Life Insurance and Retirement Plans

CaringKind 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 CaringKind. Please check the guidelines pertaining to your donor advised fund.

Corporate Giving

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

100% of your donation supports New York City individuals and families affected by an Alzheimer's or dementia diagnosis.

Please contact Carol Berne at 646-744-2905 or cberne@caringkindnyc.org if you would like additional information.

Mother's Day & Father's Day Campaign

April 2016

Dear Friends of CaringKind,

You never forget the moment you learn that your loved one has Alzheimer's disease. For me, the call came on a cold January afternoon. I was 22 years old and studying in a coffee shop when my parents called to tell me the news: my 55-year-old mother had been diagnosed with early-onset Alzheimer's disease. It was a call I never expected. I felt immensely lost, confused, and scared – for me and my brother, our family's future and, most of all, my mother. How would we ensure mom received the best quality of care for her best quality of life? How would we become caregivers for the woman who'd spent her life caring for us?



And then there are the calls you make and receive that offer a different type of remembrance: The comforting voice that supports you, provides you with resources, and helps you grow into a caregiver. I placed my first CaringKind Helpline call in 2009, shortly after my mom's diagnosis. That call gave me the gift of a knowledgeable professional on the other end of the line who listened to the nuances of my struggles, fears, and hopes for my mother's care. And then put those hopes into action.

Since 2009, CaringKind's 24-hour Helpline has helped me to help my family. I found a support group for young professionals. I was connected to a network of resources to prepare me for caregiving. I was introduced to the CaringKind Junior Committee and the positive space it offered where I could share stories and support those who, like me, were impacted by the disease. And though my parents lived in North Carolina, CaringKind helped me find support and resources there, services that benefited my family and helped us make the difficult decisions.

Many of us are all too familiar with the tough calls: deciding care can no longer be offered at home, selecting a nursing home, identifying high-quality care, carrying out end-of-life wishes with respect and dignity. Because of the many calls I'd already made to CaringKind, I felt more prepared, competent, and supported when my family faced those decisions.

On August 15th, 2015, my mom passed away at the age of 61, in the arms of her husband, her daughter, and her 20-year-old son. This is the devastating reality of Alzheimer's disease: there is still no cure. But there is care, and support to ensure our loved ones receive the best care we can provide in the fight against Alzheimer's.

My mom's spirit could light up a room with a glow matched only by her smile. Her generosity was matched only by her compassion. And in the end, her kindness was matched by her care.

I'm proud to support CaringKind and the world they have helped me create: one where those with Alzheimer's disease and related dementias are cared for with kindness and compassion. I support them so families can access the resources that made the journey a bit easier for my family. I support them in memory of my mother, in honor of all of those who cared for her, and in hope for a world where daughters and sons, husbands, wives and partners, friends and caregivers won't have to make these calls. I hope you'll join me.

Sincerely,



Laurel Crosby
Junior Committee President

P.S. You can also make a secure donation online at www.caringkindnyc.org/SpringCampaign.

Planning Today for Tomorrow

When CaringKind expanded to the third floor in March 2013 to build our Program Center for Education, Training, and the Early Stage, we were able to do so because of the generosity of individuals who had planned ahead and left us in their estate plans. The bequests that we receive are from grateful clients who wish to give back in exchange for the support and help they received during the very difficult journey of caring for, or knowing, an individual with dementia.

Planned giving is a way to support CaringKind through your will, a retirement account, a trust, or other vehicles to make a charitable contribution after your death. Through estate planning, you can make a meaningful impact helping others

who are heartbreakingly affected by a diagnosis of Alzheimer's disease or a related dementia. For more than 30 years we have been a leader in dementia care, setting the gold standard for care.

Though we all hope for a cure or an effective treatment or therapy, we know that in its absence, the best

course of treatment is good care. Your contribution enables us to plan ahead so that we can develop innovative, creative, and leading-edge caregiving initiatives to ensure that caregivers today and tomorrow have a place to turn for the best in dementia care.

Gifts of any size are appreciated and every single gift is important to helping us. Please see the **Ways to Give** section on bequests on page 16 for further information or please contact Carol Berne at 646-744-2905 or cberne@caringkindnyc.org.

For more than 30 years, we have been a leader in dementia care, setting the gold standard.

Know Your Charity

The following organizations ARE NOT affiliated with CaringKind:

- Alzheimer's Association
- Alzheimer's Association, New York City Chapter
- Alzheimer's Disease Resource Center (ADRC)
- Alzheimer's Drug Discovery Foundation
- Alzheimer's Foundation of America
- Bright Focus Foundation
- Long Island Alzheimer's Foundation (LIAF)
- Staten Island Alzheimer's Foundation (SIAF)

Reducing Risk for Cognitive Decline in Your 20's, 30's and Beyond

By James Campbell

When we think about reducing the risk of disease, contradictions come to mind: the friend who ate right and exercised but had a heart attack at 50 vs. the relative who lived happily into his 90's despite smoking and rarely walking more than a block. "Reducing Risk for Cognitive Decline in Your 20's, 30's and Beyond: What is or isn't in our control?," CaringKind's 28th Annual Meeting, brought together a panel of experts on October 26 to address what these contradictions mean for Alzheimer's disease.

Board Co-Chair Benjamin Jenkins commenced the event by welcoming guests and thanking the meeting's sponsors, Bill and Jane Brachfeld and the RBC Foundation USA. Following his remarks, CaringKind President & CEO Lou-Ellen Barkan framed the evening by recalling her mother's interest in controlling her weight through diet. A key theme she shared was "connecting what we eat to who we are and who become." At the same time, she noted, there are less malleable factors, such as a person's sex, that might increase the probability of cognitive decline.

Barkan then handed the stage to Dr. Max Gomez, Emmy Award-winning WCBS-TV journalist who has moderated several CaringKind events,

this time leading the discussion in front of a record audience. Joining Dr. Gomez were Richard S. Isaacson, MD, and Sarah Janicki, MD, MPH.

Dr. Isaacson brought his expertise in Alzheimer's disease risk reduction and treatment. Dr. Isaacson is the director of the Alzheimer's Prevention Clinic, Weill Cornell Memory Disorders Program, and director of the Neurology Residency Training Program at Weill Cornell Medical College/NewYork-Presbyterian Hospital as well as the bestselling author of *The Alzheimer's Diet: A Step-By Step Nutritional Approach for Memory Loss Prevention & Treatment*.

In her work, Dr. Janicki uses different analyses to research the ways hormones influence the risk of cognitive decline in certain populations. Dr. Janicki is an assistant professor of neurology at the Lucy G. Moses Center for Memory and Behavioral Disorders in the Neurological Institute of New York at Columbia University and a faculty member of the Gertrude H. Sergievsky Center at Columbia University Medical Center.

Dr. Gomez was careful to bear in mind that many reject the idea that Alzheimer's is preventable, prompting Dr. Isaacson to respond to those who've had family members who "do



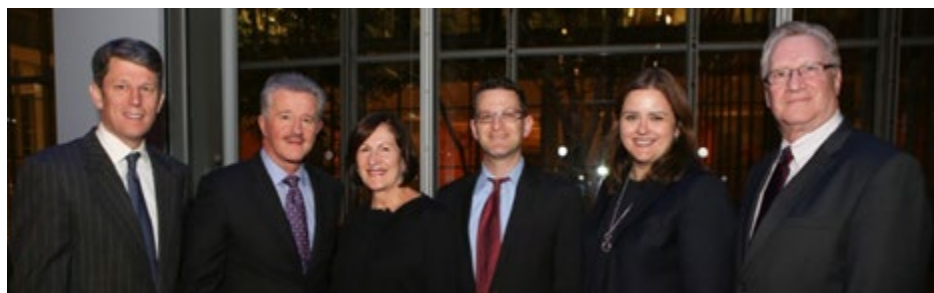
Dr. Max Gomez moderates the discussion between Dr. Richard Isaacson and Dr. Sarah Janicki

everything right," only to succumb to Alzheimer's. "The key," Dr. Isaacson said, "is that there is not a one-size-fits-all approach" to risk reduction. Instead, "the field is going to a more personalized approach," where each person's genes, metabolic, endocrine, cardiac and other medical profiles should influence an individualized method to reduce the risk of cognitive decline. He also emphasized that genes are not necessarily destiny, but that they work in concert with the environment, diet, exercise and other factors.

Dr. Janicki echoed the personalized method by emphasizing work being done with massive genetic datasets to develop "a genetic fingerprint" for each patient. Though a genetic fingerprint might be inalterable, she cited modifiable risk factors. One such factor is education, and Dr. Janicki called upon the audience to tell their younger family members to stay intellectually active through their teens, 20's, and 30's.

Following a Q&A, Executive Vice President, Director of Programs & Services, Jed A. Levine, closed the evening by highlighting the role advancements in medicine played in the preceding discussion.

James Campbell is a freelance writer based in New York City. He holds an MA in International Affairs from The New School and has written for various academic and human rights organizations.



From Left: Benjamin Jenkins, Dr. Max Gomez, Lou-Ellen Barkan, Dr. Richard Isaacson, Dr. Sarah Janicki and Jed A. Levine

The inaugural Loraine Halis Family Caregiver Conversation Series was held on November 5 in the Dorene Scolnic Training Center.

This series is dedicated to the memory of Loraine Halis, and was introduced by her daughter, Dorene Scolnic. Dorene is a social worker, and served as the primary caregiver for her mother.

This annual event is designed to educate caregivers and provide an evening of thoughtful conversation about caregiving issues. The series launched with a program entitled "Reducing Caregiver Stress: The Value of Mindful Meditation" and was attended by more than 60 caregivers who participate in CaringKind programs.

Jed A. Levine moderated the conversation between Dr. Patricia Bloom, Clinical Associate Professor of Geriatrics at the Mount Sinai School of Medicine, and Joan Griffiths Vega, a support group leader at CaringKind who is also trained in Mindfulness Based Stress Reduction. The program included a demonstration of mindful meditation techniques that caregivers could implement at home to help reduce stress. A reception followed the program.



Dorene Scolnic (center) is joined by her brother and former Board member Jeff Halis (second from right) and her family at the Loraine Halis Family Caregiver Conversation.



From Left: Joan Griffiths Vega, Dr. Patricia Bloom and moderator Jed A. Levine listen intently to questions from the audience.



From Left: Keith Kelly, Kevin Kelly, Ed Kelly and Janet Kelly

On October 19, members of The Kelly Gang met to celebrate the dedication of The Kelly Gang, Inc. Training Room in the third floor program center.



Board member and 2015 Forget-Me-Not Gala Chair Linda LaGorga (third from left) is joined by family and friends on October 5 for the dedication of "The Mike LaGorga Caregiver Lounge," named in honor of her father.

The Mike LaGorga Caregiver Lounge, located in the heart of the third floor program center, offers caregivers and other clients a comfortable and welcoming environment to socialize, or spend a moment of respite or relaxation.

A Conversation with David Hyde Pierce & David Shenk: "The Forgetting" 15 Years Later

Date: Monday, May 2, 2016

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

Time: Check in: 5:30 p.m.
Program: 6:00 p.m.
Book Signing & Reception: 7:30 p.m.

RSVP: By Monday, April 25, 2016
Crissy Vicendese at 646.744.2927 or
cvicendese@caringkindnyc.org
www.caringkindnyc.org/CaregivingLecture

The Charles Evans Lecture on the Art and Science of Caregiving, established in 2013 is designed to recognize caregiving as an important social, political, policy, and spiritual issue that merits thoughtful discussion and discourse.

*This event is free of charge, and open to the public.
Formerly Known As Alzheimer's Association, NYC Chapter*

2016 Forget-Me-Not Gala

Monday, June 13, 2016

Gala Chair

Jonathan S. Henes
Kirkland & Ellis MMP

Master of Ceremonies

Nigel Barker
Photographer and TV Personality

Live auction conducted by Jamie Niven

**For more information, contact Crissy Vicendese
at 646-744-2927 or visit caringkindnyc.org/gala.**

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- Richmond Behavioral Associates
- Micro Essential Laboratory
- Holliswood Center
- Alliance Homecare
- AlphaCare of New York
- St. John's University, School of Education
- Pro Construction
- Staten Island Care Center
- Eyeglasses Unlimited Inc.
- The Staaten
- Boro Park Cutting Tools
- Paramount Oral Surgery
- Millenium Medical Billing
- Solo Fitness and Well Being

In-Kind

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- Atria Senior Living
- Woodloch Resort
- The Vanderbilt at South Beach
- Pure Protein
- Feel the Beat DJ
- La Strada Restaurant
- Farmer Brothers
- Ferry Ads
- GoGo squeeZ
- Craft Studio
- TapSnap
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g-iii.com

Congratulations and thank you to the Athletes to End Alzheimer's team who ran in the 2016 United Airlines Half on March 20! Together they raised **\$110,000** to support CaringKind's free programs and services.

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



Athletes to End Alzheimer's 2016 Events Calendar

May 1	TD Five Boro Bike Ride
May 14	TackleALZ NYC
July 24	Panasonic New York City Triathlon
November 6	TCS New York City Marathon

caringskindnyc.org/athletes

Proud to support
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Junior Committee Update

By Marielle Mindlin Bernstein

Former Junior Committee President

The Junior Committee's mission is to grow a network of young professionals who support and engage each other and the larger Alzheimer's community, advocate for legislation, and raise funds to finance research and programs. We make an impact by volunteering directly with the community and advocating for legislation. However, we know that funds are what is needed to treat and cure this disease. That is why fundraising is an important aspect of the Junior Committee that we take very seriously.

In fiscal year 2015, the Junior Committee raised \$135,000 from various events. In August we held our annual allocation meeting, where CaringKind staff members presented proposals of programs and services that we could fund with the money we raised. We sincerely thank Lou-Ellen Barkan, Jed A. Levine and the entire staff for giving us this opportunity. Committee members appreciate the opportunity to choose how to distribute the funds they've raised, and then to see their impact in the community.

After the presentations, Junior Committee members asked questions and discussed our options. The final vote was to fund:

- \$10,000 for Wanderer's Safety Program grants
- \$20,000 for one Dementia Care Training for Professional Caregivers
- \$5,000 for the Support Group Leader Breakfast
- \$3,500 for the Medical and Healthcare Professional Outreach Program



From Left: Treasurer JC Hay, Secretary Maxine Squires, President Laurel Crosby and Vice President Brittany Krygowski comprise the new Junior Committee Executive Board

- \$10,000 for Advocacy and Public Policy Activities
- \$3,500 for the African American Outreach Program ESMA Physicians Dinner

Our fundraising efforts will not end until a cure is found and programs and services are no longer needed. That is why on October 2, the Junior Committee hosted our annual gala. This year's gala took on an Old Hollywood theme and was an evening of glitz and glamour at the Broad Street Ballroom. Our sponsors Remy Martin and People's United Bank, along with our ticket sales, donations, and silent auction, helped us to raise a record-breaking \$80,000! Guests were treated to fully stocked bars with alcohol donated by Remy Martin, Tito's Handmade Vodka, Bonnie Rose Whiskey, Hendrick's Gin, Barefoot Wine, Piper Sonoma Champagne, Lagunitas Beer, and Tequila Avión. The night ended with delicious desserts donated by Ovenly, Fattycakes, Sweetly Brooklyn, and the Flour Pot, as well as gourmet popcorn donated by Butter and Scotch.

We know it is our generation's responsibility to change the trajectory of this disease, so we wanted to recognize someone who is doing just that. We presented the Junior Committee's Science Advisor, Dr. Andrew Teich, with an Outstanding Achievement Award for devoting his career to Alzheimer's research. Dr. Teich runs a laboratory at Columbia University, where his research has identified a possible

therapeutic target that appears to be important for treating the disease.

A special thank you to our gala chair Lea Marra, the gala steering committee, and the CaringKind staff for their endless hours of effort putting this event together. We hope that you will all join us at our 2016 gala, as well as other Junior Committee events throughout the year!

A message from Laurel Crosby:

"When I first attended a Junior Committee meeting in January 2013, I realized there was something powerful happening at the CaringKind office. This group of young professionals was volunteering their time, ideas, and fundraising efforts as a united front against Alzheimer's disease and related dementias, while also creating a positive space for those whose family members had the disease. As I watched my mother battle early-onset Alzheimer's disease, the JC was one of the few spaces where I no longer felt so alone in the caregiving experience. Two years, two Walks, and a position on the 2015 gala steering committee later, I'm honored to lead the JC as its president. 2016 brings us a new brand, and a new opportunity to leverage the incredible success Marielle Mindlin Bernstein set in place. This year, we aim to expand and diversify engagement opportunities for all members; to equip each member with Alzheimer's knowledge and the critical work of CaringKind, and to cultivate the next generation of engaged philanthropists to create a compassionate world for those with Alzheimer's, while advancing us toward a world without Alzheimer's."

Wanderer's Safety Program Update



ELIZABETH BRAVO SANTIAGO
Director of Wanderer's Safety Program
esantiago@caringkindnyc.org

As you know, the New York City Chapter of the Alzheimer's Association has decided it is in the best interest of those we serve and the organization to separate from the National Alzheimer's Association. By doing so, we return to our roots as a local independent, stand-alone charity, where we began over 30 years ago.

Although we may have changed our name, we will continue to enroll persons with Alzheimer's or related dementias, as well as their caregivers, in our Wanderer's Safety Program and to coordinate with the New York City Police Department



Bill Ritter presents Officer Richard Fazio with the Community Service Award



From Left: NYPD Detective Catherine Nelson, NYPD Sergeant Anthony Caggiano, Lou-Ellen Barkan, NYPD Commanding Officer Deputy Inspector Vanessa Knight and David Hyde Pierce

and other emergency responders to respond to reports of missing and found persons with Alzheimer's disease or dementia in New York City.

We honored our longtime alliance with the NYPD and their dedication to help keep persons with Alzheimer's safe, by presenting Transit District One Community Affairs Officer Richard Fazio with the Community Service Award at our annual Walk in October.

Over the last several years we have worked together during Roll Calls, National Night Out, and meet-and-greet events. This networking has helped us reach hundreds of caregivers and provide them with resources and information concerning wandering issues and access to our free programs and services.

The CaringKind Wanderer's Safety Program will continue our strong partnership with the NYPD. We will work together to resolve wandering incidents and educate the community during special events and community board meetings. The NYPD will also help connect us to caregivers who need an identification

product for a family member or friend who is at risk of wandering. Scholarships are available for all persons living within the five boroughs of New York City diagnosed with Alzheimer's or a related dementia who cannot afford to pay for enrollment. Scholarships are provided through generous support from the Warner Foundation, members of the New York City Council, assembly member David Weprin, and the CaringKind Junior Committee, among other funders.

To enroll online or via telephone, visit

caringkindnyc.org/WanderSafety or call 646-744-2918.

Early Stage Center Update



LAUREN VOLKMER
Director of Early Stage Center
lvolkmer@caringskindnyc.org

It's been a busy time in the Harry and Jeanette Weinberg Early Stage Center. In the past year, Maria Mursch, formerly of our Social Work Services department, has stepped into the role of Manager of Early Stage Center, and I have transitioned from our Training department into the role of Director of Early Stage Center. We maintain a full schedule of groups each week at the Early Stage Center, providing a wide range of support and activities for our participants.

Our core Early Stage groups are:

MemoryWorks® - Mentally stimulating exercises including word games and brain teasers that help keep the brain active and alert

Connections - A lively and fun discussion about trivia, current events, history, and more

Support Groups - A place for early-stage people to talk with others about the experience of living and coping with their illness

These groups meet weekly for an hour and a half and provide participants with the opportunity to engage in activities and discussion within a supportive environment. Early Stage Center participants may also attend our weekly Movie Matinee (popcorn included!), socialize or read the

newspaper in the Community Room, or use the computer. We also provide a rotating schedule of special programs including volunteerism, yoga, and the creative arts. As such, our clients have participated in many special events over the past few months.

In September, at the suggestion of our group participants, we offered a three-session, peer-driven workshop titled "Sharing Strategies for Living with Early Stage Memory Loss." Participants shared experiences and ideas and worked together to create a list of helpful, practical tips. The strategies and tips were so plentiful that we will be publishing them in future editions of the newsletter. The group was excited to share their stories of how they adapt to situations on a daily basis, and hoped that others would use the information to better understand how to manage the symptoms of Alzheimer's and other forms of early memory loss.

On October 18, the Early Stage Center "Walking Thunder" team raised both funds and awareness at our annual Walk. Each year, Early Stage Center participants come together with their family and friends to show their strength and resilience by walking in Riverside Park. In the weeks leading up to the Walk, Center participants volunteered their time to assist our staff in preparing Walk materials. There was much laughter and camaraderie throughout the process, and all involved felt that they were contributing in a meaningful way to the cause.

In November and December, we launched a pilot of our first-ever improvisational theater group. The group was modeled on The Memory Ensemble™, a collaboration between Northwestern University and Lookingglass Theatre Company. The group was led by our staff social workers with support from various theatrical

professionals. We particularly thank Johnna Scrabis, an improviser and teacher with the Upright Citizens Brigade Theatre, for her active role in the collaboration. Participants met for five weeks to play and create with one another in a supportive environment. We were impressed and pleased to see the degree of focus, spontaneity, and emotional exploration that occurred in the groups. And there was a large, healthy dose of laughter as well!

Most recently in March, again driven by our participants' requests, we offered a workshop for early-stage people and their families titled "Planning for the Future." Daniel G. Fish, Esq. gave an overview of the legal and financial documents that everyone should have. We then enjoyed lunch followed by a facilitated discussion about end-of-life care. For some it was a reminder of conversations they have already had, for others it was the first step towards stating their wishes to their family. These are often difficult conversations, but still very important.

Looking ahead, we will expand our services even further. More educational events for participants and their care partners, specialized arts-based programs, and our annual Early Stage Gathering are in the works. Although no one chooses to have early-stage Alzheimer's as part of their own or their family's story, we are here to support people in this stage with creativity, humor, and dignity.

**An interview
is required to
participate in the
Early Stage Center.
For more information,
please call the
Helpline:**

Queens



CHESHIRE SCHANKER

Queens Outreach Social Worker
cschanker@caringkindnyc.org

At CaringKind, we recognize that in a city as big as New York, it is important to look at the parts as well as the whole. This notion is the origin of my position: Queens Outreach Social Worker, a cross between a social worker and outreach worker created to tailor our support and resources to best fit the residents of Queens. This position is supported by a generous grant from the Stavros Niarchos Foundation. The dual responsibilities of providing direct service and support and conducting outreach complement one another, and are unique to this position. As a social worker, I do in-depth work with individuals and families who are facing the decisions and challenges associated with Alzheimer's disease and related dementias. I provide education, care planning assistance, and counseling around the emotional impact of the illness. In my outreach role, I liaise with the community by speaking directly to caregivers and service providers in each neighborhood of the borough. I gain an up-close look at services available in Queens and build relationships with an array of providers to call upon when the need arises.

Working with dementia caregivers and service providers in Queens has been inspiring. Queens is one of the most diverse places in the country. As such, programs must not only accommodate different languages, but also display the cultural sensitivity necessary for all to flourish. When I ask program directors what languages their members speak, they often smile and respond, "What don't they speak?" While some programs accommodate

this diversity by dividing into groups of different languages, with bilingual or multilingual programming, other programs specialize in one language community. It is a privilege to connect caregivers with meaningful services. A caregiver I spoke with recently was overjoyed when I told her that her mother could attend a mostly Korean-speaking day program. While it was not in her neighborhood, the program provided transportation so she could attend and spend time with people who share her language and culture.

Conducting outreach in the community, I have found myself at nursing homes, adult day programs, assisted living facilities, naturally occurring retirement communities, and respite programs, and seen that Queens clearly cares about its residents with dementia. I have visited programs such as Ridgewood Bushwick, which provides a cozy apartment with round-the-clock professional caregivers for affordable overnight respite stays, and Queens Community House, which offers multiple levels of adult day care so that a person progressing through the stages of Alzheimer's never has to discontinue the program. Due to the borough's size, it is important for us to know what is out there and where it is. For example, placing a relative in a nursing home in Neponsit would not be feasible for a caregiver living in Woodside. Knowing about both dementia and Queens helps me provide superior support to its caregivers.

Another component of my role is presenting our Understanding Dementia Seminar to caregivers. I am thrilled to announce that we have partnered with four organizations throughout Queens where I will be regularly presenting the seminar: AHS Caring Communities Adult Day Care Center in Astoria, Atria Senior Living in Kew Gardens, Self Help Alzheimer's Resource Program in Bayside, and Ohel

Social Services in Far Rockaway. I will be rotating between these sites every four months, giving one presentation each month. I am excited that caregivers throughout Queens will have access to this invaluable program. AHS Caring Communities has even volunteered to provide care during the presentation, making it the only Understanding Dementia meeting in the city with the capability for caregivers to bring the person they are caring for with them.

From the educational seminars to site visits to direct client work, every facet of my role complements the others and helps fully realize the goal of providing Queens-based support. I know that for every exhausted caregiver to whom we provide assistance, there are so many more who do not realize that these services exist. This motivates me to find new and innovative ways to reach the caregivers of Queens to let them know CaringKind is here for them, and even closer than people think!

The Bronx



CAITLIN MCCURN

Director of Research & Grants
cmccurn@caringkindnyc.org

At CaringKind, we have always been committed to serving all New Yorkers who have been impacted by Alzheimer's disease and related dementias. Throughout our 30-year history we have launched awareness campaigns, developed outreach programs, and opened satellite locations throughout the city to ensure that underserved communities are aware of and able to access our programs and services, which are available free of charge.

Nowhere has this work been more important than in the Bronx, where the needs are great. African Americans and Hispanics make up the majority of the borough's residents and are at increased risk of developing Alzheimer's. Bronx residents also face cultural, linguistic, and socioeconomic barriers that limit their ability to access healthcare and support services. By focusing our attention on diverse communities with unmet needs, CaringKind has successfully addressed some of the barriers faced by Bronx caregivers and persons with dementia. Over the past three decades we have broadened our outreach approach to ensure that a greater number of Bronx caregivers, persons with dementia, community providers, and professionals are aware of and can access our services. Our African American, Latino, Medical and Healthcare Professional Outreach, and Wanderer's Safety Program staff have worked extensively in the Bronx, providing informational presentations and direct services to local residents who are concerned about Alzheimer's disease or related dementias. Through these outreach efforts we have improved Alzheimer's awareness and generated greater interest in our programs and services. I am pleased to share with you some of the additional ways we have enhanced care and support for individuals in the Bronx:

- We enrolled over 5,000 Bronx residents in our Wanderer's Safety Program.
- We responded to more than 4,900 Bronx callers through our 24-hour Helpline.
- Our social workers have consulted over 1,200 Bronx caregivers.
- We established caregiver support groups throughout the Bronx.
- We educated English and Spanish speaking caregivers

at Understanding Dementia seminars held twice a year at locations in the Bronx.

- We trained hundreds of home health care aids from home care agencies located in the Bronx through our Dementia Care Training for Professional Caregivers.
- In 2014, we held our first Latino forum on Alzheimer's at Lincoln Hospital.
- We collaborated with churches in the Bronx to implement our Family Caregiver Workshops in Spanish.
- We have received several referrals from St. Barnabas and Montefiore since 2014 via our Rapid Referral program.
- We presented Mount Carmel Pharmacy, one of our closest partners in the Rx for Care Pharmacy Card Program, with a community service award.
- We presented at all the NYPD precincts in the Bronx, collaborated with Community Affairs and worked with several housing and transit police in the borough.

We pride ourselves on working collaboratively with an extensive network of organizations that provide services for individuals with dementia and their caregivers. In the Bronx our partners include home health care agencies (Cooperative Home Care Association, Home Care Associates, Kings Harbor Multicare Center); hospitals and medical centers (Lincoln Medical and Mental Health Center, Bronx-Lebanon Hospital, Calvary Hospital, Montefiore Medical Center, St. Barnabas Hospital, Westchester Square Hospital); senior services facilities (Bronx Wood Senior Center, Riverdale Senior Services Melrose

Senior Center, PSS, Parkchester Enhancement Program for Seniors); adult day programs (ARCH Care Senior Life Day Care Center, Morningside Adult Day Program, Providence Rest Adult Day Program, R.A.I.N.); residential care facilities (Morning Side Nursing Home, Hebrew Home for the Aged at Riverdale, Belmont Boulevard Senior Housing, Jewish Home and Hospital, Methodist Home for Nursing & Rehabilitation, Williamsbridge Nursing Home); churches, women's shelters and others (Senior Bridge, Visiting Nurse Services of New York). These partners make referrals to our 24-hour Helpline and enable us to facilitate support groups, education meetings, workshops for family caregivers, and community presentations. They assist us in registering persons with dementia in our Wanderer's Safety Program and circulate bulletins to assist in the timely return of missing persons with dementia. None of the inroads we have made in the Bronx would have been possible without their support.

We are proud of the progress we have made increasing our presence in the Bronx and connecting its residents to our programs and services. As we move forward, we hope to broaden our reach in a borough where there is still much more to accomplish. In the future we hope to place a full-time social worker in the Bronx to fill the gap in social services and provide hands-on guidance and support for families who have been impacted by Alzheimer's disease or a related dementia.

**Continue reading
to learn about
our work in
Staten Island and
Brooklyn!**

Staten Island



JED A. LEVINE

Executive Vice President, Director of Programs & Services
jlevine@caringskindnyc.org

The borough of Staten Island presents unique opportunities for CaringKind to serve the residents and professionals who live and work on the Island. The so-called “Forgotten Borough” is anything but forgotten by the hardworking staff and volunteers of CaringKind. We have worked diligently to develop relationships and foster collaborations with the social service, aging, faith-based and human services communities to bring our programs to families facing the challenges of caring for a relative with Alzheimer’s or a related disorder.

Since 2002, when we expanded our territory to serve all five boroughs, all of our programs and services have been available free of charge to offer help, hope, and practical assistance. We have also held community presentations and hosted other events on Staten Island. Here is some of our recent activity:

- Our 24-hour Helpline has responded to hundreds of callers seeking the personalized help and support that we offer.
- Trained support group leaders lead groups on Staten Island.
- Former City Council member Vincent M. Ignizio has provided funding for enrolling Staten Island residents in the lifesaving Wanderer’s Safety Program.
- City Council member Debi Rose has hosted programs for CaringKind, specifically focused on the minority population.

- For the first time, we brought our annual Walk to Staten Island’s South Beach, connecting hundreds of families with the resources of CaringKind.
- Our Latino and Chinese Outreach programs have held workshops and community presentations to reach the growing diverse population on Staten Island.
- Over 900 Staten Island residents are enrolled in the Wanderer’s Safety Program.
- CaringKind’s Wanderer’s Safety Program associates have also done presentations for all three NYPD precincts on Staten Island, held workshops for three Staten Island Community Boards, and worked with the Parks and Recreation Department.
- Nate’s Pharmacy has opened their doors to us and hosted an information table, as well as a Wanderer’s Safety Program enrollment day.
- We participated on the Staten Island InterAgency Council where we networked with colleagues, leading to community and agency presentations at a wide variety of settings including:
 - VNS
 - CCM (Comprehensive Care Management), now Center Light
 - Carmel Richmond Health Care Center
 - Staten Island University Hospital
 - Advantage Care Physicians
 - Eger Health Care Center
 - Meals on Wheels
 - CASC
 - JASA
 - Vanderbilt Nursing Home
 - JCC Stapleton Senior Center
 - Community Health Care of Richmond
 - Temple Emmanu-el
 - Blessed Sacrament
 - New Dorp Moravian Church
- Staff from Staten Island nursing homes have attended our nursing home conferences on improving care for persons with dementia, including the most recent one in April 2015 focusing on Palliative Care for Persons with Dementia, which was co-sponsored by 1199 SEIU and the Center for the Advancement of Palliative Care.
- Home care workers from Staten Island have completed our Dementia Care Training for Professional Caregivers program.
- Many Staten Islanders have signed up as advocates.
- Staten Island families have received financial assistance through our Special Assistance Fund.
- Staten Island Community TV hosted two hour-long programs led by CaringKind staff, bringing much needed information and resources to the residents of Staten Island.
- Early in 2015 we led an all-day workshop for clergy and lay leaders from the Staten Island Council of Churches, thanks largely to Deacon Frank Ali.

We have made great strides connecting Staten Islanders with the guidance and support we provide at CaringKind and spreading our message of hope and help throughout the borough. We recognize that there is still much work to be done, and have made plans to place a full-time social worker on Staten Island, who will aid families right on the island. If you’d like to host a community presentation or event on Staten Island, please contact our 24-hour Helpline at 646-744-2900.

Brooklyn

**MATT KUDISH**

Senior Vice President of Caregiver Services
 mkudish@caringkindnyc.org

CaringKind has deep roots in Brooklyn. Over the last 30 years, we have developed rich community partnerships with a wide array of service providers, spanning the full spectrum of services available to those affected by dementia. From diagnostic centers to the District Attorney's office, from geriatricians to geriatric psychiatrists, from adult day programs to homecare providers, from respite care to long-term care facilities, from the Borough President to the Kings County Supreme Court, CaringKind has presented for, collaborated with, and referred to several entities throughout the borough.

One of our longest standing relationships continues to be with the Brooklyn Alzheimer's Disease Assistance Center (BADAC) at SUNY Downstate. After many years of cross referrals and collaborations on many of our initiatives, including caregiver support groups and our Wanderer's Safety Program, we learned that the BADAC had lost a vitally important funding stream that supported the essential work of its Director of Social Services, Lorna Walcott-Brown. Lorna has been supporting Brooklyn's Alzheimer's and dementia community since 1993. Her institutional knowledge of both the needs of Brooklyn's Alzheimer's community as well as the myriad community-based supports available is vast and unmatched, and she was also the sole link between the medical and social services provided by the BADAC to persons with dementia and their caregivers. In her role at the BADAC, Lorna provided psychoeducation to families affected

by dementia about the disease and its course. She connected families in need to the many services available to them, providing support along the way as they encountered challenges while navigating the various systems needed to secure care. Lorna has also facilitated a caregiver support group since 2000, providing group members with much-needed emotional support and a space to share their complicated feelings with others going through similar experiences. Additionally, she enrolled several dozens of persons with dementia and their family members in our Wanderers Safety Program during her tenure at the BADAC.

We knew that the elimination of Lorna's position at the BADAC would be a profound loss for Brooklyn's most vulnerable adults and their caregivers, so we hired Lorna to join our staff in July 2012. In the years since, Lorna has worked with her colleagues to further enhance her own skills and knowledge, as well as contribute to growth among her network and their knowledge base.

Even before Lorna joined our team formally, we were committed to meeting the needs of the Brooklyn dementia community. For over 20 years we have offered support groups in English, Spanish, and Chinese throughout the borough; and we began offering our Understanding Dementia Seminar monthly in 2005. In recent years, thanks to the support of the Stavros Niarchos Foundation, we have expanded even further into Brooklyn, offering a number of Family Caregiver Workshops throughout the borough in both English and Spanish, as well as a specially developed workshop to meet the unique needs of the Orthodox Jewish population.

Our Diversity Outreach staff and Speakers Bureau volunteers have conducted countless presentations to culturally diverse groups at senior

centers, churches and other religious institutions, community boards, and community-based organizations. Through our cultural arts program, connect2culture®, we have trained staff at some of Brooklyn's leading cultural institutions to enhance their ability to provide specially-designed programs for people with dementia and their caregivers. Future plans include collaborating with even more cultural entities to partner with us to provide the highest quality programming for people with dementia and their caregivers close to home.

Most recently, recognizing the need in other areas of Brooklyn for the services Lorna provided at the BADAC, last year we launched a pilot program with NYU Lutheran where Lorna is available one day each week to provide information, education, and support to individuals and families served by their diagnostic and treatment team.

On March 11, in collaboration with the Brooklyn Borough President's Office, we hosted a conference at Borough Hall for Brooklynites affected by or interested in dementia. The conference included welcoming remarks by Deputy Borough President Diana Reyna and presentations by several CaringKind staff members on topics including enhancing communication, managing challenging behaviors, and creating meaningful activities. The event was attended by more than 250 people – caregivers, professionals, and providers alike. The conference was also generously supported by the Stavros Niarchos Foundation.

As we continue to expand even more deeply in Brooklyn, we will look for new opportunities to continue to meet the needs of the growing dementia community. Visit our website to learn about our exciting new developments.

We are proud to announce strategic partnerships with the LEAD Coalition and Cure Alzheimer's Fund to promote advocacy and research.



A special luncheon, hosted by CaringKind Board Emeritus Heath McLendon was held at the River Club on January 5, to celebrate CaringKind's partnership with the Cure Alzheimer's Fund.

Front row, from left: Cure Alzheimer's Fund CEO Tim Armour and Lou-Ellen Barkan

Back row, from left: Heath McLendon, Cure Alzheimer's Fund Vice President Sally Rosenfield, Cure Alzheimer's Fund Chairman of the Board Jeff Morby, Cure Alzheimer's Fund Board member Jacqueline Morby, Jed A. Levine and CaringKind Board Co-Chair

Cure Alzheimer's Fund is a nonprofit organization dedicated to funding research with the highest probability of preventing, slowing or reversing Alzheimer's disease through venture-based philanthropy. Since its founding, Cure Alzheimer's Fund has contributed

more than \$38 million to research, and its funded initiatives have been responsible for several key breakthroughs. Fully 100% of funds raised go directly to research – the Board of Directors covers all overhead expenses. Cure Alzheimer's Fund supports some of

the best scientific minds in Alzheimer's research who work at premier research institutions across the country and regularly confer with one another on progress and impediments in their research and constantly share their data.



Leaders Engaged on Alzheimer's Disease (LEAD) is a diverse and growing national coalition of 82 member organizations including patient advocacy and voluntary health nonprofits, philanthropies and foundations, trade and professional associations, academic research

and clinical institutions, home and residential care providers, and biotechnology and pharmaceutical companies. LEAD is co-convened by USAgainstAlzheimer's and Volunteers of America. The coalition works collaboratively to focus the nation's strategic attention on Alzheimer's

Stay tuned for updates about how advocates can get involved!

disease and related dementias and to accelerate transformational progress in care and support to enrich quality of life, detection and diagnosis, and research leading to prevention, effective treatment and eventual cure.

What Does it Mean to Participate in Aging and Dementia Research?

Every 67 seconds someone in America develops dementia. There is an urgent need to research causes, treatment, and prevention of the disease. While funding is always an issue in research, finding volunteers is just as big a challenge! Estimates suggest that at least 50,000 volunteers, including healthy elders, persons with dementia, and caregivers, are needed for existing studies.

Over the past decade, care for individuals with dementia has improved because of the willingness of individuals to participate in research. Studies suggest that most individuals decide to participate in research out of altruism, the desire to help others. Other reasons for participation include wanting to learn about the newest treatment approach or having the opportunity to contribute towards the advancement of science that might directly benefit their children and grandchildren. Some participants want to take an active role in their healthcare, combat feelings of helplessness, do something interesting, and receive free study-related medical treatment. Aging and dementia research offers hope for people with dementia and their families by involving them in finding treatment for the disease in the future.

What are the advantages of participating in research?

Study volunteers may have the opportunity to receive promising new treatments that are not available outside of a clinical trial, try treatment methods with fewer side effects than usual care, have regular access to medical experts, and help others who have the same disease. There are, of course, potential risks to consider when deciding whether

to join a particular study. For example, there may be side effects associated with the experimental treatment or it may not be effective. However, researchers and ethics committees work together to maximize safety, reduce risk, and ensure that participants know all of the risks and potential benefits so they are fully informed. Participants sign a consent form that spells out all of the procedures, provides them with a way to ask the researcher additional questions, and informs them that they can withdraw. Safety monitoring plans are described in all research studies and may include local and national government agencies, such as the FDA.

What can study participants expect?

Although every study is different, most follow a similar process. Each potential participant will first speak with a study coordinator about the goals, procedures, possible risks, and benefits of the study as well as any questions or concerns he or she may have. Participants will then be asked to sign an informed consent form that contains all of the information about the study. Participants will be asked to do different things depending on the type of study and whether the study is recruiting healthy elders, caregivers, or persons with dementia or mild cognitive impairment. For example, in a genetic study, participants may be asked to give blood or consider a lumbar puncture. In a clinical trial, including prevention studies for those at risk for developing Alzheimer's disease, participants may take an experimental medication. Other studies may include neuroimaging (e.g. MRI or PET scans). Many studies ask participants to take paper and pencil tests that assess cognitive functioning,

such as memory and concentration. Some studies require multiple visits, others just a few. While participating in a study usually involves coming to a research center, typically at a hospital or medical school, others offer home visits. It's important to keep in mind that not every study is right for every volunteer! You should select a study that feels right for you and your family. For example, someone who is very claustrophobic might not pick a study that includes an MRI, and someone who is very busy and travels a lot may not participate in a study that requires many visits to the clinic. However, with over 100 studies currently recruiting healthy elders, persons with dementia or caregivers, there may be a study that feels right for you.

What are the rights of research volunteers?

Signing the consent form does not waive any legal rights or alter participants' ability to end their participation at a later time. Participants are given a copy of the consent form in case they have questions later. Any participation in a study is always completely voluntary. People are free to decline to participate for any reason at any time, and their decision will in no way affect any services or care to which they are otherwise entitled.

How can people find local research programs?

There are many ways to learn about current research studies, including contacting your local medical centers and visiting a database through the National Institutes of Health at www.clinicaltrials.gov or the CaringKind website at www.caringkindnyc.org.

**Please call our
24-hour Helpline
at 646-744-2900
to register.**

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

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:**

AHS Caring Communities
Atria Senior Living, Kew Gardens
Heights & Hills
Riverstone Senior Life Services
The Elly & Brochie Kleinman OHEL
Regional Family Center
Selfhelp Alzheimer's Resource Program

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, resources, and services available.

Upcoming Dates in English:

May 10	5:30 - 7:30 p.m.	Manhattan
May 12	6:00 - 8:00 p.m.	Queens
May 13	12:00 - 2:00 p.m.	Manhattan
May 18	5:30 - 7:30 p.m.	Manhattan
May 18	6:00 - 8:00 p.m.	Brooklyn
June 1	3:00 - 5:00 p.m.	Queens
June 10	12:00 - 2:00 p.m.	Manhattan
June 14	5:30 - 7:30 p.m.	Manhattan
June 15	1:00 - 3:00 p.m.	Manhattan
June 15	5:30 - 7:30 p.m.	Brooklyn
July 7	3:30 - 5:30 p.m.	Queens
July 8	12:00 - 2:00 p.m.	Manhattan
July 12	5:30 - 7:30 p.m.	Manhattan
July 20	5:30 - 7:30 p.m.	Manhattan
July 20	6:00 - 8:00 p.m.	Brooklyn
August 3	6:00 - 8:00 p.m.	Queens

Upcoming Dates Just for Professionals:

June 8	3:00 - 5:00 p.m.	Manhattan
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Upcoming Dates in Spanish:

May 11	12:30 - 2:30 p.m.	Manhattan
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Upcoming Dates in Chinese:

Please call our Helpline for upcoming meetings in Cantonese and Mandarin.

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:

Manhattan	
May 17	5:30 - 7:00 p.m.
July 19	5:30 - 7:00 p.m.

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:

May 5	5:30 - 7:00 p.m.	Manhattan
June 2	5:30 - 7:00 p.m.	Manhattan
July 7	5:30 - 7:00 p.m.	Manhattan
August 4	5:30 - 7:00 p.m.	Manhattan

Family Caregiver Workshops

During this 10-hour workshop series, 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. Attendance is required at all workshops in a series.

Upcoming Series Dates:

Wednesdays	May 4, 11, 18, 25	12:00 - 2:30 p.m.	Manhattan
Thursdays	May 5, 12, 19, 26	5:30 - 8:00 p.m.	Manhattan
Tuesdays	June 7, 14, 21, 28	12:00 - 2:30 p.m.	Manhattan
Thursdays	June 9, 16, 23, 30	5:30 - 8:00 p.m.	Manhattan
Tuesdays	July 5, 12, 19, 26	5:30 - 8:00 p.m.	Manhattan
Wednesdays	July 6, 13, 20, 27	12:00 - 2:30 p.m.	Manhattan
Upcoming Series Dates in Spanish:			
Mondays	May 2, 9, 16, 23	5:30 - 8:00 p.m.	Manhattan

Monthly Education Meetings

Upcoming Series Dates (all meetings from 6:00 – 8:00 p.m.). RSVP online for Monthly Education Meetings at www.caringkindnyc.org/educationreg.

May 9

Bringing Comfort to People With Advanced Dementia

- What does comfort look like for someone with advanced dementia?
- Identify specific strategies for bringing comfort
- Learn how to include comfort as part of advance directives

Speaker: Deirde Downes, MSW, LCSW, Corporate Director of Social Work and Supportive Care Programs, Isabella Geriatric Center

June 6

connect2culture®: Cultural Arts Programs for People with Dementia and their Caregivers

- Learn about CaringKind's cultural offerings
- Hear about programs available throughout the city
- Discover how to create culturally based activities on your own

Speakers: Nancy Lee Hendley, MFA, Manager of connect2culture;
CaringKind's connect2culture community partners

July 11

Dementia and Driving: Keeping Everyone Safe

- Reduce conflict over driving decisions
- Ease the transition, facilitate conversation and promote safety
- Learn to use a Dementia and Driving Decision Aid (DDDA) to determine when a person should stop driving

Speakers: Victoria Traynor, RN, PhD in social gerontology, Associate Professor, University of Wollongong; Diane K. Pastor, RN, MBA, NP-C, FNAP, PhD in dementia nursing, Associate Professor, University of North Carolina at Wilmington, School of Nursing

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, healthcare 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.

Upcoming Dates:

Manhattan

May 2	5:30 - 7:00 p.m.
May 16	5:30 - 7:00 p.m.
May 26	5:30 - 7:00 p.m.
June 6	12:00 - 1:30 p.m.
June 20	5:30 - 7:00 p.m.
June 23	5:30 - 7:00 p.m.
July 18	5:30 - 7:00 p.m.
July 28	5:30 - 7:00 p.m.

Upcoming Dates in Chinese:

Manhattan

April 21	2:00 - 4:00 p.m.
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**Please call our
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to register.**



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