

caringkind

The Heart of Alzheimer's Caregiving

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WINTER 2017

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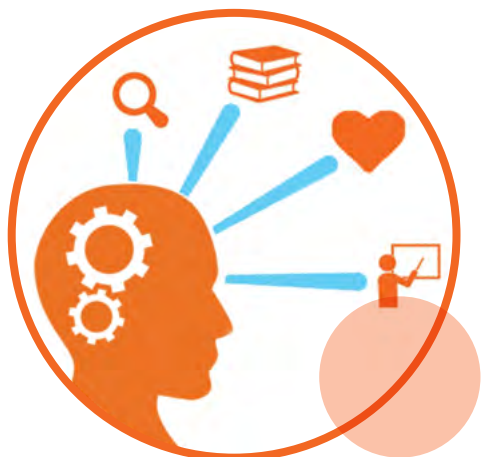
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Dear Friends,

What's the difference between a toaster and your favorite charity? For some, not a lot. Recently, a friend of mine was looking for a new toaster. Nothing mattered to her – not cost, not performance.

She didn't even care if it could toast two or four slices. The guiding criterion was that it had to be the right shade of yellow to match her kitchen.

I had to chuckle a few weeks later when she called to tell me that it shorted out and blew the circuit breakers in the house.

Unfortunately, many people take the same uninformed approach to the charities they support. They give money almost blindly based on a TV commercial they like, a vague allegiance to a celebrity spokesperson, and yes, even to a charity's color. They donate their hard-earned money not really knowing how the charity operates, the range and effectiveness of its programs, the experience and professionalism of its staff, or how it spends the money you give.

In this issue of the newsletter, we have brought together knowledgeable and impressive experts who will introduce you to the tools and resources you need to determine if your favorite charities have the fundamental foundation that makes them worthy of your support.

Form 990 Return of Organization Exempt From Income Tax for 2016. The form includes sections for organization information, financial data, and a summary of the organization's mission and activities.



On page 6, attorney Daniel Kurtz, the former head of the Charities Bureau for the Attorney General's office, which has oversight of all charities in New York State, and his partner, Shveta Kakar, share their insights about evaluating charities.

In a compelling essay on page 8, our own Ed Cisek, Vice President of Program Evaluation, describes CaringKind's commitment to providing the best services possible by continually evaluating and improving our programs to meet the evolving needs of those we serve.

So how do you know if you are making a wise investment in a charity? Like you should if you're buying a toaster, do your homework. Become an informed donor. Understand where your money goes. How much goes to programs? Who works there? Who's leading the organization day to day in the trenches, and at the highest levels of the Board of Directors?

At CaringKind we are very proud of who we are and how we operate. We invite you to inspect our financial records.



LOU-ELLEN BARKAN
President & CEO
lbarkan@caringkindnyc.org

Our 990 – a form we must file every year with the IRS – contains detailed financial information as well as our accomplishments in the previous year.

I also urge you to visit us, if you haven't already. What will you see? You'll see more than 30,000 square feet of space, brimming with activity at all hours of the day. You will see more than 60 dedicated CaringKind professionals and support staff who work tirelessly to make sure that caregivers and people with dementia get the services they need, when they need them. You will find our 24-hour Helpline – a lifeline to thousands of New Yorkers every year. You will find hundreds of free support groups, workshops, and educational seminars for caregivers and people with the disease. You will find a homey, warm, and welcoming state-of-the-art Early Stage Center, where we offer an array of programs and activities designed specifically for individuals in the early stage of dementia, and so much more, all for free.

As pioneer retailer Sy Syms would say, "An educated consumer is our best customer." Here at CaringKind, we couldn't agree more.

Dear Readers,

As local options for Alzheimer's care and support increase, we are proud that we remain New York City's most trusted source of information, education, support and guidance that we have always been for over 30 years.



JED A. LEVINE

Executive Vice President, Director of
Programs & Services

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In December, we celebrated one year of returning to our roots as an independent 501(c)(3) charitable organization, incorporated in New York State, serving New Yorkers. We have deep roots in this city we love. Our program staff, including our 18 licensed social workers, are experts in the details of the city's resources. Which day program is the best fit for a family calling from Park Slope? What is the best advice that can help expedite a Medicaid application? What are the most effective resources for diagnosis and treatment? For participating in a clinical trial? No matter how difficult the question or problem, CaringKind can make it easier to find a solution.

Our MedicAlert® NYC Wanderer's Safety Program is unique, due to our intimate relationship with the NYPD Missing Persons Unit and time-tested protocols that work. We send bulletins to hospital emergency departments, social work and security departments, and the media, with the family's permission. Equally important, we stand by the family's side to provide comfort and support during the harrowing time when a relative with Alzheimer's is lost on the streets of New York City, confused and vulnerable.

Our programs are unique because they are integrated. We connect the families of missing persons to our social workers to establish a long-term care plan. We connect families with an interest in art, music, or dance to our partners at the Lincoln Center Moments program and

other cultural institutions. We connect clients calling our 24-hour Helpline to an array of programs, including over 90 support groups and numerous specialized trainings. We provide extraordinary programs for those with early stage dementia, unmatched by anything else in New York City.

I am proud to say that, thanks to the generosity of our donors, all of our services remain free of charge. And now that 100 percent of your donation stays in New York City, we can do much more for the many New Yorkers who need our help. Know your charity!

We are proud of our new name, CaringKind, and what that name broadcasts to the world. We are New York City's premier expert in dementia caregiving. We are a place where you can tell your unique story, get the support you need, and get a head start accessing the local resources you need to survive the difficult burden of caregiving. You don't need to take this journey alone. Call us at 646-744-2900 at any time of the day or night and we will be there: a hand to hold, an exhale of relief and a bright spot in what can feel like the darkest of times.

CaringKind in 2016

Our **24-hour Helpline** responded to over **10,000** calls from family caregivers, persons with the disease, professionals in the field, and the "worried well."

Our **Social Work Services** provided over **4,500** in-depth, personalized consultations.

Our **Wanderer's Safety Program** enrolled over **25,000** people, helping to ensure that persons with dementia who wander will be safely found and reunited with their families.

Our **Dementia Care Training for Professional Caregivers** trained over **350** home care workers to become specialized in dementia care. Through our web-based job matching tool, **Together We Care™**, we connect families with aides trained by CaringKind.

The Well-Spent Dollar



By Daniel Kurtz & Shveta Kakar

How do you know which charities to donate to? Charitable giving, which in the old days used to be directed by word-of-mouth recommendations and donations to your local church, is now a much more challenging minefield. Charities are increasingly involved in awareness campaigns, there are complex networks of cause marketing, and social media has changed the landscape indelibly. Charities of all sizes are using social media campaigns, from YouTube videos, to Twitter, Facebook and others, to engage goodwill and awareness for their corporations. More information is put in front of us than ever before, but the question is, how do you know if your charitable donations are dollars being well-spent on the cause(s) you care about?

How do you know if your charitable donations are dollars being well-spent on the causes you care about?

There are several services, places you get information from, and things you can do to better inform yourself and determine if your money is being mostly spent on the charity's 'mission' i.e., how effectively is the charity in carrying out its mission. One of the first places

you can look to search for a charity is GuideStar.org, where you can access the organization's Form 990, the basic I.R.S filing document for nonprofits, for each year. The Charities Bureau of the New York State Attorney Office is another place where the charity's Form 990s are made universally available to the public. You can simply run a search for the charity's name on its website, www.charitiesnys.com, and access the filed Form 990s for every year of the organization's history. When it comes to larger charities, the information available on the Charities Bureau website is unique. Not only are the Form 990s available, but if the charity raises more than \$500,000, it is also required to file audited financial statements with the New York State Attorney General, that are made publicly available on the site as well. This threshold is slated to change to \$1 million by 2020.

While somewhat daunting, the Form 990 has a host of information on the organization's financial health and governance. Besides the summary of the basic financial information on the first page (revenues and expenditures), the second page is key. Before donating, the first thing you want to know is "What is the Charity's Mission?" For instance, charities may be committed to the same health issue, but may support different focuses such as scientific research, promoting public awareness, or providing patients with care and information. The next question you should be asking is "How Effective is the Organization in Carrying out its Programs in Support of that Mission?" Page 2 of the Form 990 (Part III) is where you need to look. It describes the organization's mission, its efforts to achieve the mission and the resources devoted to it. On page 6 of the Form 990 (Part VI) is a series

of questions that inform you about the organization's governance, including its governance structure, the size of its Board, and if governance decisions are delegated, among others. Importantly, it lists how many independent Board members there are, a key indicator of good governance to start with. On page

The most valuable insight comes from contacting the organization itself and getting involved to see for yourself.

7 (Part VII), the Form 990 also provides detailed information on the names and compensation of officers, directors, key employees, and highly compensated contractors. The Form 990 also provides you with other relevant information, including whether there have been any serious issues or problems at the organization, which would be disclosed on one of the schedules at the back. All of this information allows you to make your own assessment and judgment about the charity.

There are, in addition, several independent organizations that do the work for you. Charity Navigator evaluates nonprofits based on their financial health, accountability, and transparency, including how the charity will use its support today, how well it has sustained its programs and services over time, and its level of commitment to being accountable and transparent. After evaluating this information, it gives them star ratings accordingly,

with four stars as the highest rank. Another group is the BBB Wise Giving Alliance, affiliated with the Council of Better Business Bureaus, which has free review of charities. Applying 20 accountability standards, the alliance will specify whether the charity meets the BBB standards or not.

Of course, you can conduct your own due diligence beyond the Form 990 and ratings by reviewing the charity's website, its publications, annual reports, and news reports. The most valuable insight, of course, comes from contacting the organization itself and getting involved to see for yourself.

Daniel Kurtz chairs Pryor Cashman's Nonprofit + Tax-Exempt Organizations Group. As the former Assistant Attorney General-in-Charge of the Charities Bureau of the New York State Attorney General's Office and co-author of one the leading treatises of New York Nonprofit Law, Dan has earned a national reputation for servicing the full range of needs of his nonprofit clients. In his role, he advises on corporate and governance issues; sponsorship and charitable fundraising opportunities; endowment administration and investment; indemnification; and charitable solicitation laws along with an array of exempt organization tax issues. In addition, he regularly handles business combinations, including joint ventures, sales of assets, mergers, consolidations and sophisticated reorganizations and restructurings for his nonprofit clients. Dan has also conducted numerous internal investigations and handled

litigations brought by civil enforcement and regulatory authorities against nonprofits, playing a key role in many groundbreaking cases in this area.

Shveta Kakar is a Partner in Pryor Cashman's Nonprofit + Tax-Exempt Organizations Group. She advises nonprofit clients on governance issues, counseling them on matters that could potentially ripen into government investigations or litigations, and conducts internal investigations and also represents them in governance disputes and in investigations by civil and regulatory authorities. She routinely advises Boards on their duties and responsibilities, the legal framework governing nonprofits and maintaining tax-exempt status, and counsels them on conflicts, internal controls and crisis management. She has written and spoken extensively on these issues.

caringkind

The Heart of Alzheimer's Caregiving

Invites you to the 5th Annual Charles Evans Lecture on the Art & Science of Caregiving

Here But Not Here – Learning to Live with Ambiguous Loss

Join **Jed A. Levine**, CaringKind's Executive VP and Director of Programs and Services, as he moderates a candid discussion with **Dr. Pauline Boss**, widely recognized for her groundbreaking research on the theory of ambiguous loss, and author of *Ambiguous Loss: Learning to Live with Unresolved Grief*, and family caregiver **Karin Marder**. Dr. Boss's research and practice have revealed that those who suffer ambiguous loss, losses without finality or resolution, bear a particular and challenging burden. This year's lecture will focus on the loss, trauma, and resilience people experience when coping with "ambiguous loss" after an Alzheimer's or dementia diagnosis.

Monday, April 24, 2017 - 6:00pm

The Times Center

242 West 41st Street (between 7th & 8th Avenues) NYC

RSVP:

www.caringkindnyc.org/CaregivingLecture
Crissy Vicendese at 646-744-2927 or
cvicendese@caringkindnyc.org

This event is free of charge, and open to the public.

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.



The Importance of "Doing Your Homework"



EDWARD CISEK

Vice President of Program Evaluation
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"Tiger" by Bud Blake (May 6, 1974)

Before you make an important purchase – a car, for example – chances are you do some research. You'll probably check the car's performance, fuel efficiency, and safety ratings, and perhaps you'll read other drivers' reviews. You trust that the car company has a good system in place to test the car and make improvements as needed. You also hope that independent consumer organizations are unbiased in their ratings of the vehicle.

When you donate to a charity, shouldn't you do that same level of research? And don't you want a system in place to ensure that your money is spent efficiently and in ways that truly make a difference? Many nonprofits are quick to promote their programs with individual stories of success. But as Carl Sagan said, "extraordinary claims require extraordinary evidence."

More and more frequently, private foundations that fund programs are requiring that the programs be evaluated. They ask questions such as: "Are the programs we fund being implemented as intended?" "Are the programs reaching the intended audience?" and "What are the program outcomes for individuals, organizations, and the community?" Savvy individual donors are also beginning to ask these same questions. Program evaluation professionals and departments seek to provide the answers.

Program evaluation is the systematic collection, analysis, and use of information in order to determine how well a program is doing, and, ultimately, to improve a program.

CaringKind showed its commitment to program evaluation over six years ago by hiring a full-time evaluator. There are now two full-time evaluators on staff. At CaringKind, we engage in many types of evaluation including, but not limited to, the following:

Needs Assessment.

We assess the needs of our clients in the outer boroughs as we continue to expand our efforts to reach all communities in New York City.

Formative Evaluation.

We keep track of the amount and characteristics of the people we serve, as well as their satisfaction with programs. Program evaluation staff often observe programs and interview staff to ensure a program is running as planned.

Outcome Evaluation.

We survey education and training participants to see how the program has affected their knowledge, attitudes, and use of caregiving skills.

Most importantly, all this information is shared with staff to make any necessary program adjustments. After adjustments are made, programs are evaluated again. And the cycle continues.

**EARLY STAGE ALZHEIMER'S
CLINICAL TRIAL**



Imagine making
AN IMPACT

Consider taking part in a clinical trial that is currently enrolling to treat early stage Alzheimer's disease.

To qualify, participants must:

- Be between 55 and 79 years old
- Have at least 8 years of education
- Have noticed, or have had a loved one notice changes in your memory or normal, everyday behavior
- Attend all study visits with a study partner with whom you have frequent contact
- Be in good general health

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“My mother died recently and I was her caregiver during the six years that she had Alzheimer’s disease. I phoned the Helpline many times over the years to ask for assistance. Now that I am no longer an active caregiver I plan to make a donation specifying that the money go to the Helpline so that other caregivers can benefit the way I have. How will my contribution be used?”

Please accept our sincere condolences on the passing of your mother. Thank you for allowing us to share in your caregiving journey and for considering supporting CaringKind. CaringKind is New York City’s leading expert on Alzheimer’s and dementia caregiving, and our Helpline, the program to which you intend to donate, is the heart of CaringKind.

Since 1986, Helpline Specialists have been providing callers with the most up-to-date information, education, and support regarding Alzheimer’s disease and related dementias. Helpline Specialists are often a caller’s first contact with CaringKind, and as such they receive intensive training to ensure they convey information in a caring, compassionate, and competent manner to all callers. Helpline Specialists hold a wealth of knowledge about Alzheimer’s disease, our organization, and other social service agencies throughout New York City. Answering calls on the Helpline is a unique and important job, and your contribution will help ensure that Helpline Specialists continue to receive professional development and access to current resources.

Imagine that you are a fly on the wall in the Helpline office. Several Helpline Specialists are answering phone calls. One is speaking English, another, Spanish. Some calls are quick – registering for a seminar or workshop, others may last

for the good part of an hour – where to go for a diagnosis, assistance in finding a support group, or how to handle an impending crisis. One caller may be in despair or feeling overwhelmed. There may seem to be no light at the end of the tunnel. The Helpline Specialist listens, asks questions, offers support, and provides suggestions. The caller’s anxiety lessens, and she is assured that CaringKind will be there for her throughout her caregiving journey.

As stated above, there are many reasons why people contact the Helpline. Some call because they are experiencing memory loss while others call because they are caring for a person diagnosed with a type of dementia. Many call to learn about the services we offer and to register for our free education seminars and training programs. Professionals call to consult about one of their clients, and students call to acquire more information for class discussions or term papers on geriatric care and to learn about volunteer opportunities. People also call when they feel alone or confused; they call for emotional support because living with Alzheimer’s disease can be overwhelming at times. And many people make repeat calls because they feel empowered by our Helpline Specialists.

As of July 2016, the Helpline has responded to, on average, over 725 interactions per month. Interactions include telephone



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The 24-hour
Helpline is available
around the clock,
365 days a year.
646-744-2900

calls, emails, in-person meetings, and postal mail inquiries to the Helpline.

Contributions have supported our goal of professionalizing the Helpline. In the past, our Helpline team consisted of mostly trained volunteers who came for weekly four-hour shifts. With the support of donors such as you, the Helpline has gone from volunteer-driven to professionally staffed by Master’s level social workers, or those with a related degree. In addition, we have been able to hire bilingual and bicultural staff, enabling us to meet the needs of our callers in their native language and in a culturally appropriate manner. This helps callers feel more comfortable, most especially when discussing difficult family situations. We have also been able to upgrade our information packets from printed flyers folded in small brown envelopes to two-sided folders customized with information addressing the information needed by each unique caller.

With contributions such as yours, we hope to further expand and modernize the 24-hour Helpline and continue to help all New Yorkers during their caregiving journeys.

Interview with Dr. Richard Isaacson



RICHARD S. ISAACSON, M.D.

This is the third and final part of Jed A. Levine's interview with Dr. Richard Isaacson.

Richard S. Isaacson, M.D., serves as Director of the Alzheimer's Prevention Clinic, Weill Cornell Memory Disorders Program, and Director of the Neurology Residency Training Program at Weill Cornell Medicine/NewYork-Presbyterian Hospital.

Dr. Isaacson specializes in Alzheimer's disease (AD) risk reduction and treatment, mild cognitive impairment due to AD and pre-clinical AD. His research focuses on nutrition and the implementation of dietary and lifestyle interventions for AD management.

Jed A. Levine (JL): Acknowledging that it will take time to know if you're truly preventing Alzheimer's, can you expand upon the name of the Alzheimer's Prevention Clinic?

Dr. Richard Isaacson (RI): While I go back and forth on this, I still feel comfortable with calling it the Alzheimer's Prevention Clinic because we enroll people in trials and care for their family members with Alzheimer's. It's a holistic approach. By seeing families together, you can see a mom has Alzheimer's and find manifestations in the daughter's profile. The son may be more like the father. We're learning an immense amount about the science, but also a lot about

the psycho-social aspect of Alzheimer's prevention.

As an example, we're finishing our first study examining the first 100 patients of the Alzheimer's Prevention Clinic. We asked them to do a comprehensive survey of where they were when they arrived and where they are now. We learn about their attitudes towards being a patient in an Alzheimer's prevention clinic and learning about their genetic profiles. These are 30 to 70-year-old people from all walks of life. And what we're finding is absolutely fascinating.

At some point we're going to find a drug to either prevent or cure Alzheimer's disease, and when that blockbuster drug comes out, we will be treating patients for primary and secondary Alzheimer's prevention. There will be psycho-social and behavioral elements that are going to need to be understood. The good news about our practice is that we're actually learning about this now.

JL: You're studying it already?

RI: We are attracted to the science and fascinated by the psychology. We are confirming that when someone learns that they have an APOE-4 gene, their compliance goes up.

The REVEAL study taught us that when people first learn they have the gene, they are anxious. But after a year, that goes away. Even if they understand that having the gene doesn't mean they will definitively get Alzheimer's, knowing that they have the gene improves compliance with the recommendations. So, we're learning about how to give this message.

The name of the clinic is the Alzheimer's Prevention Clinic, but throughout our brochures and flyers, you don't see the words "Alzheimer's" and "Prevention"

next to each other. We have a FAQ where we respond to the question, "Can we truly prevent Alzheimer's?" The answer is no; we cannot definitively prevent Alzheimer's and we are a long way from being able to do so. In the interim, our philosophy is to educate a person to take a clinically precise approach towards their own health, follow them, learn from them and, we believe, have a positive impact on their brain and body health.

This message is tough to deliver, so to get the right language, we did market testing, had focus groups, used internet messaging, and operated a Facebook page. I got yelled at when I used the words Alzheimer's and prevention together. I hear things like, "My mom did everything right and she still got Alzheimer's." I've heard this over and over.

The problem is most people can do everything right and still get Alzheimer's. But in my opinion, and based on the best available evidence, there is a subset of people who may be able to either delay Alzheimer's long enough to be candidates for an effective therapy or simply outlive the onset. These people effectively prevent their Alzheimer's.

That's the reason to empower people to use a scientifically based, yet honest approach towards brain health. That's why I'm still okay with the language. Today, although I still get tomatoes thrown at me, it's much better than it used to be.

JL: Initially, I had a strong reaction. I asked "Who is this guy? Who does he think he is?"

RI: We're very cautious about what we say, but today there is more information. In 2015, there was a study about exercise improving some cognitive function for some people in the early stages of the

disease. Another group studied healthy people aged 65 and over who exercised different amounts each day, ranging from 25 to 55 minutes. The amount of time made only a modest difference, but everybody had some improvement in cognitive function or on their cognitive tests.

This goes back to your first question, “Why am I doing Alzheimer’s prevention?” I have four family members with Alzheimer’s disease. I’m completely biased. I want to prevent this disease like everyone else, but I’m also living it too.

JL: I’ve heard Dr. Reisa A. Sperling say similar things.

RI: She’s a trailblazer! You know, I am so appreciative for CaringKind’s willingness to have an open conversation about this. I want to be responsible in the message and communicate it the right way. The evidence is starting to show up, but we still have a long way to go. People don’t even know that there are Alzheimer’s prevention trials going on. Some people think of Alzheimer’s prevention as enrolling in clinical trials. But just the fact that someone can come to a place and learn about ongoing Alzheimer’s prevention trials is reason enough to have a clinic like this.

JL: How do people find the clinic and apply? Are you looking for more subjects or are you overwhelmed with subjects?

RI: In three years, we’ve grown from one to 12 staff members. We have two neurologists that see Alzheimer’s prevention patients, more than any other similar facility, but there are still only two of us. The clinic completely exploded. My colleague and I have a six-to-eight-month waiting list. We’re doing the best we can, but we need to hire more people.

When the A4 trial got going and people were unsure if they should enter, we saw a lot more patients. Now, because we are in the “big city,” we have a stream of patients and an influx of calls every time a brochure, new study, or news report comes out. As an example, we hosted two neuropsychologists from Puerto Rico. We shared our entire approach with them so they can build and implement the model. In Puerto Rico, the patient will most likely access the service through primary care, which makes a lot of sense.

JL: That’s where people should be getting their primary healthcare, through their primary care physician.

RI: Primary care is where the five vital signs, like pain, are examined. Cognitive health is a vital sign too. It should be the sixth vital sign. Primary care physicians are better suited to this work than neurologists. When that blockbuster drug finally arrives and we have to decide who gets it, maybe neurologists should be the prescribers, but for risk assessment and intervention, we need a variety of healthcare practitioners to handle the work.

I hope that this field takes off within a few years. Hopefully, we are laying the groundwork and can accelerate the timeline. Even if we can accelerate it a little bit, I’ll be satisfied.

JL: Some studies show that there is a relationship between sleep, duration of sleep, quality of sleep and development of Alzheimer’s disease. For example, there was a study about sleeping on your side. I’m a side sleeper.

RI: I’m a side sleeper too. The study was for mice, but it appears that sleeping on your side opens up the glymphatic system so amyloid can be more easily flushed out.

Sleep is really important. The analogy that I use for my patients is not perfectly scientific, but it’s a good way to explain it.

You can exercise, which is the only thing that we have in 2016 to definitively break down amyloid. Exercise busts amyloid. But, how do you get the amyloid out of the brain? Through sleep. Amyloid is basically taken out to the curb as we sleep through the glymphatic system.

There’s also findings about melatonin and research on variances between people who remember their dreams versus people who don’t. I see these kinds of things in my clinical practice, but I don’t understand the patterns yet.

This is an example of the biological principle of synergy; a combination of factors makes a difference. Nutrition plus exercise plus sleep. Then you add stress reduction. Then you add vascular risk factor modification. When you add all these things that have shown evidence to make a difference and are low risk, that’s the biological principle of synergy.

Last year, there was an article in *The Lancet* that said one in three cases of Alzheimer’s is preventable. That’s a big statement. If we can delay a stroke or a heart attack by six months, a year, two years, and can use the term prevention, I think there’s also encouragement to use the term for patients worried about cognitive decline. That’s the key.

JL: Thank you so much for sharing your thought on this very complicated subject. I know our readers, like me, have learned a lot.

A Year of Transition, A Year of Service



MATT KUDISH

Senior Vice President of Caregiver Services
mkudish@caringkindnyc.org

For over 30 years, CaringKind has been New York City's central address for Alzheimer's and dementia care and support. And this has never been truer than it is now, following our disaffiliation from the national Alzheimer's Association in December 2015.

No one knows New York better than New Yorkers. By returning to our roots as a local New York City-based nonprofit, our clients receive the highest caliber information, education and support from our expert staff, all of whom are based right here in New York City and truly understand the complexities of caring for a person with dementia in this complex, urban environment.

We are in every borough, collaborating with our long-standing community partners and forging new relationships throughout the elder care network; visiting service providers from adult day programs to respite organizations, and to long-term care facilities in order to better understand the myriad

ways in which care is being provided throughout the city; and staying on top of the ever-changing complex network of systems of care across New York City, including benefits and entitlements such as Medicaid.

Whether you are speaking with a Helpline Specialist, meeting with a social worker, attending an educational seminar, training program, support group, or participating in our Early Stage Center, no one understands how to best support you on your journey more than the dedicated staff of CaringKind.



To be sure, the full array of programs and services we offer – all available free of charge – remain not only intact but are more vibrant and active than ever. And our staff is not only as committed as ever, but continues to grow to ensure that we are prepared to meet the ever-increasing demands of New Yorkers affected by a dementia diagnosis. In the last year, thanks to the generosity of our supporters, we have grown significantly, adding even more program staff to support our work with clients.

We have increased the number of Helpline Specialists available to answer your calls to our 24-hour Helpline. We have added additional social workers

to respond to your more complex emotional and concrete needs, assist you in developing a long-term plan, and address the emotional impact of seeing someone you care for decline. We have expanded more deeply into Brooklyn, Queens, Staten Island, and, soon, the Bronx, offering many of our programs and services in your local community. We are proud to be offering our education meetings in more neighborhoods and languages than ever before, making it even easier for you access the information you need without having to travel far. Our Training staff has expanded to provide even more trainings for family and professional caregivers in English and Spanish and, for the first time, trainings in both Mandarin and Cantonese. In our Early Stage Center, we have added a third social worker, dramatically increasing the number of programs offered each week, and the number of clients served. Our support group network continues to offer over 90 groups every month throughout every borough, with new groups being started regularly across the city.

Over 15,000 New Yorkers walk through our doors each year, and even more are now accessing our robust programs and services in their local communities. But the number of people affected by dementia in New York City is constantly growing.

Very often we hear from our clients, "I wish I had called you sooner." With your help we can increase public awareness about the invaluable resources available through CaringKind and ensure that every New Yorker in need of our assistance knows that all it takes to connect with us is one call to our 24-hour Helpline. It may be the most important call you ever make.

No one knows
New York better
than New
Yorkers...and
we are in every
borough.

CaringKind closed out 2016 with media coverage in one of the largest, most widely read news outlets in the country. *USA Today* featured two incredible articles written by Lou-Ellen Barkan on Alzheimer's and dementia caregiving in a special "Fighting Alzheimer's" supplement.



One article discussed the role of caring in the absence of a cure, while the other provided common sense tips on how to ease the emotional, physical, and financial burdens of caregiving. These articles appeared both in print and online reaching over 22 million readers (and caregivers) across the nation.

Lou-Ellen was also featured on an Eyewitness News Up Close (WABC - Channel 7) segment on Alzheimer's. The Up Close program invites experts to discuss important issues impacting our New York community. Hosted by journalist and CaringKind friend Bill Ritter, Lou-Ellen discussed the changing landscape of Alzheimer's and dementia and the role of caregiving, alongside Dr. Hillel Grossman, Medical Director of the Clinical Core at the Alzheimer's Disease Research Center at Mount Sinai. (See Dr. Grossman's article about memory assessments on the following page.)

CaringKind was proud to have 100 runners who raised over \$400,000 through their participation in the 2016 TCS New York City Marathon. News 4 New York (WNBC - Channel 4) interviewed four of our runners in a live morning segment that took place at the starting line! The runners, Jennifer Balka, Senior Associate of Constituent Events at CaringKind, Nicole Henn, Roe Mercurio, and Lauren Napolitano, shared their personal stories about caregiving and what CaringKind means to them.

With November marking National Family Caregiver Month, the *New York Nonprofit Daily* newsletter noted some of the

incredible growth and expansion that's taken place this year at CaringKind – highlighting increases in our social work and other professional staff, resources for the Asian community, resources throughout the outer boroughs, and cultural program expansion.

The Everyday Heroes Project, a news site that spotlights nonprofits changing their communities, also featured CaringKind in November. Quoting Lou-Ellen, the article listed our caregiving services including support groups, counseling, and education and training seminars. CaringKind was excited to be included in this group of organizations and individuals working in collaboration to build a better world.

CaringKind has continued to support awareness surrounding Alzheimer's and dementia and the challenges unique to the Hispanic community. Featured in over 100 local events websites and calendars to great success, CaringKind participated in the 2nd Annual National Hispanic Alzheimer's Conference that took place in November and kicked off our very first Spanish-language Understanding Dementia seminar in December.

Lou-Ellen has continued to examine the most important issues confronting people living with dementia and those who care for them in "Care Chronicle" – a monthly column that runs in several local newspapers, including *Manhattan Express*, *Chelsea Now*, *The Bronx Times*, *Caribbean Life*, *East Villager*, *The Villager*, *Times Ledger*, *Brooklyn Paper*, and

Downtown Express. In recent columns, she has discussed the most common barriers to getting help, as well as tips for caregivers, family, and friends during the (often stressful) holiday season. WOR Radio (710 AM) interviewed Lou-Ellen in a segment that expanded on tips for the holidays that touched on some of the most important and helpful ways we can support caregivers and families during the winter months.

Last but not least, we were excited to close out 2016 sharing the news in several outlets, including *Guest of a Guest*, CBS New York, and NY 1, of a great fundraising event organized by Board member Anne McBride Schreiber. *Diamonds and Wine for Good* brought together jeweler Sanjay Kasliwal and winemaker Crosby Roamann (a collaboration between Anne's son Sean W. McBride and his wife Juliana), who showcased diamonds and wine for purchase – with ten percent of proceeds going to CaringKind. Many thanks to all that participated!

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When You are Looking for a Memory Assessment

By Hillel Grossman, M.D.

Everyone over a certain age has had the experience of running into a former coworker and not remembering her name; of dashing into the kitchen during halftime and not being able to recall why you are in the kitchen. What do these experiences represent? Normal aging? Emerging dementia? Early Alzheimer's disease? Does it matter how old I am? If I have a relative with dementia?

These questions should not be answered off the cuff by your neighbor's nephew who works for a drug manufacturer and pondered going to medical school. These questions require a careful collection of the facts, some reflective consideration, and a patient response.

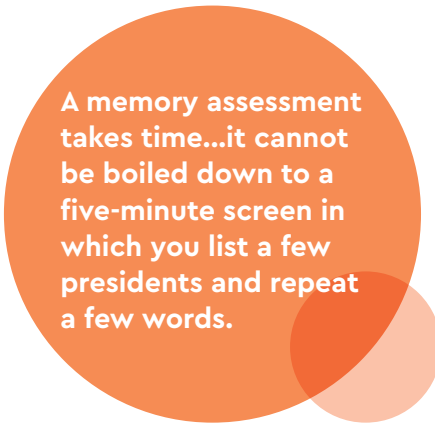
If these are your questions, then you might be looking for a memory assessment. A memory assessment has three components:

- A medical history that includes a careful questioning of memory-dependent activities, family history, educational history, and academic performance, as well as an investigation of other areas such as occupational history including toxic exposures;
- A neurological exam including a measurement of motor and sensory function and an assessment of cognition in multiple domains such as memory, language, calculations, attention, flexibility, and psychomotor speed;
- Laboratory and brain imaging.

The core of the evaluation is the history and the exam. It requires a careful and

deliberate process to get the answers. Sample questions include: Do you ever misplace things? When you can't find your wallet do you end up replacing it or does it turn up later that day?

As you might imagine, this exam takes time. It requires patience to allow an anxious and perhaps slowed patient to answer questions carefully. It cannot be boiled down to a five-minute screen in which you list a few presidents and repeat a few words.



A memory assessment takes time...it cannot be boiled down to a five-minute screen in which you list a few presidents and repeat a few words.

There are a range of brain imaging tests (head CT, MRI, FDG-PET, amyloid-PET, tau-PET) that each answer different questions about brain anatomy and function. A memory evaluation requires some specialized skill to determine which of these expensive imaging tests might be relevant to each patient. Office testing may need to be supplemented with more extensive memory testing with a neuropsychologist. These determinations of which test to obtain and how to integrate the findings into a clear diagnosis with a meaningful prognosis require particular expertise reflecting specialized training and experience.

So where can you get such an assessment? Your internist/primary care practitioner is tasked with taking care of your blood pressure, blood sugars, back pain, night sweats, and myriad other ailments and sorting through it all in a 15-minute speed-talking encounter. Your gynecologist or urologist is focused at a different level of the body. You need a memory doctor. This type of specialist may have trained as neuropsychologist, geriatrician, behavioral neurologist, or geriatric psychiatrist and may be situated at a specialty memory center. The key is that such an expert has spent years doing these diagnostic evaluations and treating people with memory disorders.

The New York metropolitan area is particularly fortunate to have three Alzheimer's Disease Research Centers (ADCs) funded by the National Institute on Aging to develop, research, and provide resources related to the diagnosis, management, and treatment of memory disorders. The ADCs are sited at the Columbia, NYU, and Mount Sinai medical centers. If you are wondering if you or someone you know needs a memory evaluation, now is the time to call.

Hillel Grossman, M.D., is the Medical Director of the Clinical Core at the Alzheimer's Disease Research Center at the Icahn School of Medicine at Mount Sinai.

A Week in the Life of the Early Stage Center



LAUREN VOLKMER

Director of Early Stage Center
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The Harry and Jeanette Weinberg Early Stage Center is a place where people with early stage dementia or Mild Cognitive Impairment (MCI) come on a weekly basis for groups that provide support, cognitive stimulation, and socialization. Participants are all aware of their memory loss and are seeking to connect with others who are “in the same boat.” Those connections are what make up the unique fabric of our program and the community spirit that exists within our walls. To illustrate this, below are some moments in time from a typical week in the Early Stage Center.

10:45 a.m. Tuesday

It's a busy morning at the Early Stage Center (ESC). Staff members are arranging tables in the Program Rooms and putting out coffee and snacks.

Participants have begun to arrive for the first groups of the week and are congregating in the Community Room. A man picks up the newspaper on the coffee table and comments on the front page headline, making a joke. Laughter drifts out into the hallway.

As each person enters the room, the others offer warm greetings: “I haven't seen you for awhile!” “It's good to be back.” “Did you get a haircut?” At 11:00 a.m., some head into their Connections discussion group, others into the seven-week special improvisational theater group.

The Community Room is now quiet, but the laughter still drifts into the hallway from the two closed Program Room doors. Later on, people will arrive for the afternoon support group, and some will stay from their morning group to view today's Movie Matinee selection: *Big* starring Tom Hanks. We're pretty sure it will be a hit.

1:00 p.m. Wednesday

The two Wednesday sections of MemoryWorks®, our cognitive stimulation groups, have ended. Some participants have brought lunch to eat in the Community Room and some have gone out to buy lunch on Lexington Avenue and bring it back. Staff members are busy changing the Program Rooms around for the afternoon program and cleaning up the dishes from the morning programs.

A participant pokes her head in the door and asks with a laugh if there are any plastic spoons around – she has bought soup but forgot to get a spoon with which to eat it. A spoon is located, a spill is wiped up, and the sound of people socializing lingers.

Members of today's support group begin to arrive and greet each other. With an average age of 59, this group is significantly younger than other ESC groups. Participants shared how comforting it is to meet others with a younger-onset diagnosis who are doing their best to cope and live life to the fullest. For now, they gather around the Community Room table, sharing stories and catching up on the events of the previous week. They are among friends.

3:15 p.m. Thursday

The Community Room and Program Rooms are quiet, and the staff is taking a cumulative deep breath following the end of our final programs of the week. Today we hosted another MemoryWorks and a Connections discussion group, plus a chair yoga class.

One participant in MemoryWorks met individually with a staff member after the group about a personal issue. She left expressing gratitude and relief to have voiced her feelings. Another staff member met with a prospective participant and his care partner. The Center turned out not to be a good fit for him, but referrals were made to other programs in the community, as well as to additional CaringKind services for the care partner.

Friday and Monday will offer time to meet with colleagues, deal with clinical issues and transitions to other programs, and respond to phone calls and emails that often get delayed on program days. Although our days are full, we are grateful for the opportunity to learn the stories of our early stage participants, and to play a small role in supporting their independence and well-being. We are grateful to the donors whose generosity ensures that this program is available free of charge to those who need it.

As Unique as the City We Serve



ANNE M. FOERG
Director of Social Work
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It is not uncommon to hear people say that they never truly understood what social workers do until they needed the assistance of one. While society recognizes social workers as people who “help,” it is their approach in doing so that is unique in relation to other “helping” professionals. A social worker is trained to see a person or a family in a holistic manner, exploring the physical, emotional, social, financial, and environmental factors that influence their movement through the world. Social work isn’t about meeting with someone and giving advice; it is about learning who a person is, where they are at, and how they see the world in order to better support them in finding new, different, and better ways to cope.

At CaringKind, our Social Work Services department is focused on providing individualized support to address the challenges inherent in caring for a person with dementia through the entire trajectory of the condition. We apply a holistic perspective, working to understand the circumstances that make a person or a family unique – personality traits, relationship patterns, family history, culture, and geographic location, to name a few – in order to better equip them in navigating rough terrain.

We counsel individuals and families over the phone, via technological avenues like Skype, and at our main office or one of our satellite locations to assist

in processing challenges, both current and future. While some need only one in-depth session to manage a crisis, more frequently, those we assist need several sessions over time to discuss their situation, dissect their particular challenges, and craft a plan to address these issues. And this might occur over several weeks, several months, or even several years.

We know good dementia care and we know New York City, and our greatest strength lies in the intersection of the two.

Just as unique as those we help, so too is our Social Work Services team at CaringKind. We have educated professionals with extensive experience in the fields of aging and disability services, hospice, and mental health counseling, all of which are rooted in this most unique of places, New York City. We immerse our staff in learning and practicing the principles of good dementia care. We know good dementia care and we know New York City, and our greatest strength lies in the intersection of the two. Families can rely on our expert guidance in navigating difficult situations made more challenging by our city’s complex systems of care.

Our experience helps families navigate the various systems with which they will likely interact over the course of their journey with dementia. We guide

people in accessing home care services, choosing an adult day program, or in finding a nursing home that will be a good fit, all through the lens of dementia and good dementia care. Just as important, we leverage relationships with other professionals and service providers in the New York City area to help our clients achieve the best outcome. We share our expertise with many organizations and professionals serving people with dementia, and in doing so, utilize these relationships on behalf of our clients, matching them with needed supports and services.

Our expertise also provides a foundation for our team to assist families in developing unique plans of care in the context of very complicated situations. We have assisted networks of friends, with no formal ties to a person with dementia, in providing care for the unfamilied individual. We have provided guidance in moving a person with dementia to New York City from a different state, as well as from a different country. When there is family conflict, often deeply rooted, we work to mediate disagreements by finding commonality in the goals to care for the person with dementia.

CaringKind’s spectrum of services operate on the same solid principles of care – education, emotional support, practical assistance – but our Social Work Services resources allow us to practice these principles in a way that is as unique as each person’s journey, whether that person has dementia or is caring for one. We meet the person where they are at and help them to move to where they would like to be.

Eight Ways Our Support Group Program is Unique



ABBY NATHANSON

Director of Support Groups

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They're totally free.

We run 2,300 support group sessions a year, in person across the five boroughs for all New Yorkers, and never charge anyone a dime for it.

You're connecting with other dementia caregivers, people who get what you're going through.

Our groups are for people who understand exactly what it means to be a caregiver for someone with dementia. It's a unique experience, and sometimes, you just want to talk to someone who gets it.

Our network is vast.

We have over 90 groups being run by 85 different people. We have groups for veterans, the LGBT community, teens, caregivers of people with specific dementias (Lewy bodies, frontotemporal, progressive supranuclear palsy) and all dementias, daughters, partners, and adult

children. We have groups for speakers of Russian, Korean, Spanish, Mandarin and Cantonese. We have groups for when you're a caregiver and groups for when you're grieving. The scale of our program means that if one group isn't a great fit, we can usually find another.

We're not running drop-in groups.

The people in the groups are committed to each other. Our leaders take the time to meet with every prospective new member to make sure the group will be a good fit. It may require a little more effort to get into a group, but once you're in, you're in with a group of like-minded caregivers who commit to come back week after week to connect with you.

Our volunteer facilitators are all trained and supervised.

We have a four-day training program accredited by the New York State Department of Education, just to prepare our leaders for our groups. Leaders undergo background checks and an application process. Dozens of leaders attend clinical supervision groups every month. All of them have regular access to a licensed clinical social worker and clinical supervisor, ongoing trainings, and resources for their groups.

Our groups are emotionally focused.

Support group members share what it's like to be a caregiver for someone with dementia, and they do so knowing that the others in the group will get it and understand it all – the exhaustion, the guilt, the anger, the humor. It's a unique space that's created just for caregivers. CaringKind has dozens of opportunities for you to get specialized information, education, and skills training, but the support groups are the best place to connect emotionally with others who know what you're going through.

When you're in a CaringKind support group, you have all of CaringKind at your fingertips.

Our support group members have regular, free access, like all New Yorkers, to our individual social work consultations, Family Caregiver Workshops, Legal and Financial seminars, educational meetings, and more. Many support group participants regularly have individual sessions with their social worker as needed when crises arise, even when they're in the group.

Groups are available for years, throughout the course of disease progression.

Until there's a cure for dementia, we're here to help you give care. Some people stay in our groups for a few months to a year, others stay in for five years or more. Just as each person with dementia is unique so is each caregiver, and we want to be with you for the long haul.





CAROL BERNE

Senior Vice President of Development
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When I was asked to write the column on “Know Your Charity,” what first came to mind was Shakespeare’s play *Romeo and Juliet* and Juliet’s quote, “What’s in a name? That which we call a rose by any other name would smell as sweet.” The implication is that names do not affect what they really are.

But, in fundraising a name means everything. And what that name represents is what you should be aware of when making a contribution to a charity. There are many Alzheimer’s related charities competing for your philanthropic dollar – through the mail, by phone calls, in print advertising, on TV and the radio, and through social media. Just because Alzheimer’s is in the charity’s name doesn’t mean it is deserving of your support.

When we left the Alzheimer’s Association, we did so because our Board of Directors strongly believed that the New York Alzheimer’s community deserved the gold standard of dementia care. New Yorkers deserved a local resource where they could attend an education seminar or a Family Caregiver Workshop, be part of a support group, and have access to 18 licensed social workers experienced in geriatrics and dementia care, all free of charge. They could also contact our 24-hour Helpline and know that our staff was knowledgeable about local resources, because they lived locally.

When you make a donation to CaringKind, or include us in your estate plans, you should know the following:

- Every program undergoes rigorous evaluation to ensure that we are meeting the needs of our clients, in the most cost-effective way;
- We are an accredited charity of the Better Business Bureau;
- 100 percent of our Board of Directors donates to CaringKind;
- We work with over 500 community partners throughout the five boroughs, and have built these relationships over 30 years;
- We have a research partner where 100 percent of your donation goes directly to a research scientist;
- We advocate locally, statewide, and nationally for funding for care and research;
- When you mail a donation to CaringKind, it goes directly to our offices at 360 Lexington Avenue in Manhattan, not to a PO Box somewhere else in the country;
- We do not exchange your name and contact information with other nonprofits or for-profit companies;
- We do not use your charitable donation to cover the costs of national advertising campaigns or direct mail marketing;
- Every dollar stays local, helping you, your family, and those you know who are affected by dementia.

Throughout this newsletter, you will learn more about what to look for in evaluating a charity, and hear from the former head of the New York State Charities Bureau on page 6. Our hope is that when you make a donation – which we hope will be to CaringKind – you will do so with confidence and the knowledge that your donation is being used wisely and well to benefit the community.

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 Donate or call 646-744-2908 or 2927. We accept MasterCard, Visa, and American Express.

Appreciated Securities

Gifts such as stocks or bonds may offer substantial tax advantages. 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.**

Planning Today for Tomorrow

When CaringKind expanded to the third floor in March 2013 to build our Program Center for Education, Training, and The Harry and Jeanette Weinberg Early Stage Center, 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 appreciation for the support and help they receive 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 18 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)



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

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.

Loraine Halis Caregiver Conversation

On Wednesday, December 7th, over 50 caregivers and friends of CaringKind attended the 2nd Annual Loraine Halis Family Caregiver Conversation. This year's program featured a reading from the book *The Long Hello* by author Cathie Borrie and award-winning actress Jill Eikenberry, followed by Jed A. Levine moderating and Anne M. Foerg, CaringKind's Director of Social Work, joining the conversation. This annual series, designed to recognize the important role of caregivers, provides an evening of conversation and thoughtful discussion about caregiving issues.

Sarah Scolnic, granddaughter of Loraine Halis, for whom this program is dedicated, opened the program. On the next page are Sarah's moving remarks about her grandmother, who was cared for in the Scolnic home. Sarah is also a member of CaringKind's Junior Committee.



From left: Jed A. Levine, Cathie Borrie, Dorene Scolnic, Jill Eikenberry, Anne M. Foerg



Jill Eikenberry and Cathie Borrie read from Borrie's caregiving memoir, *The Long Hello*.



Former CaringKind Board member Jeff Halis (left) is joined by his sister Dorene Scolnic (center left), members of the Scolnic family, and Jed A. Levine (second from right). The Halis family honored Dorene by naming The Dorene Scolnic Training Center at CaringKind.



Sarah Scolnic delivers opening remarks.

Sarah Scolnic's Opening Remarks at the Caregiver Conversation

I remember the day my dad got the call that Bubby fell and have a few clear memories of the early days of her confusion and agitation. But I was lucky to be shielded from the 'bad moments,' as we like to call them. When a disease like Alzheimer's hits a family, you have to have humor, and I believe, as the baby of the family, the timing of Bubby's move was sort of impeccable. She moved in after all my siblings had left, so the house never felt as quiet as I had hoped it would be when I was the last child in the house. We spent every day together. She was almost always silent or quiet, especially after she lost most of her speech, but every day when I came home from school I sat next to her on the couch and either did my homework or cuddled up to take a nap with her. As I recall my memories, she was always there. We would quite literally hang with and onto each other often.

When she first moved in, I didn't fully understand the disease and how long the progression could really take. I wouldn't let her fall asleep until she said 'I love you' back to me. Eventually, I gave this up, as many of you have had to give up your expectations of your loved ones. What also left around the

same time were my childhood memories of Bubby being that active grandmother. To be honest, the only Bubby I clearly remember is the one that had Alzheimer's. The one who would always cuddle me after school in silence.

When I used to think about caregiving I thought of my mom, Bubby's daughter, who cared for her for many years, and the great nurses that worked with her. But what I now believe, after being involved with CaringKind and seeing the work here, is that all people surrounding those with Alzheimer's.

The disease is difficult for any family member or friend who is around, not just the day-to-day nurses or the primary caregiver. We all have love and care to give and a reason to be here tonight. So, I am excited that we are all together once again this year to talk about how to best give our support to each other and to our loved ones who are struggling with this disease. Thank you.

Good evening, and welcome to the 2nd Annual Loraine Halis Caregiver Conversation. I want to tell you about my grandma, or as I knew her, Bubby, and why I am excited to be here tonight.

Bubby came to live with my family when I was ten years old, after being diagnosed with Alzheimer's. Before that, she was one of those active, ideal grandmothers, who came to every birthday and school play and made the best matzo balls. Some of this I distinctly remember, but, if I'm being really honest, I mostly know this from my siblings' and parents' stories. Alzheimer's disease and my relationship with my grandmother share a common hallmark: they're both intertwined by the creation and loss of memories.

"Ralph Albert Blakelock: The Great Mad Genius Returns"

On Thursday, November 10th, Louis M. Salerno, CaringKind Board member and owner of Questroyal Fine Art, LLC, held a private opening reception for the exhibit, "Ralph Albert Blakelock: The Great Mad Genius Returns," to benefit CaringKind. The sequel to a renowned 2005 exhibition, this comprehensive and groundbreaking exhibit delved deeper into the mystifying psyche of America's greatest visionary painter. With 125 works on view, the event attracted art lovers worldwide and has raised over \$40,000 for CaringKind's free programs and services.



From left: Diane Salerno; Louis M. Salerno, CaringKind Board member and owner of Questroyal Fine Art, LLC; Lou-Ellen Barkan, CaringKind President & CEO; Susan V. Kayser, Esq., CaringKind Board member emeritus; Marianne Dziuba-Fiore, CaringKind Board member

Traumatic Brain Injury: Prevention, Treatment, and the Consequences

By James Campbell

Thanks to recent Hollywood films and widespread media attention, traumatic brain injury (TBI) and chronic traumatic encephalopathy (CTE) have become cemented in mainstream discourse. Still, the facts around TBI and CTE and their relationship to Alzheimer's and other dementias remain hazy. On October 18th, at the Times Center in New York, CaringKind provided some much-needed clarity at its 29th Annual Research Meeting, the first such meeting under the CaringKind name.

During her opening remarks, CaringKind President and CEO Lou-Ellen Barkan recounted a doctor's tips for long life, one of which was "Don't fall down." The rule seemed simple, but after considering her roles as the mother and grandmother of athletes and the daughter of a veteran who suffered from dementia, she realized the rule carried immense weight. The panel she introduced reflected the issue's magnitude.

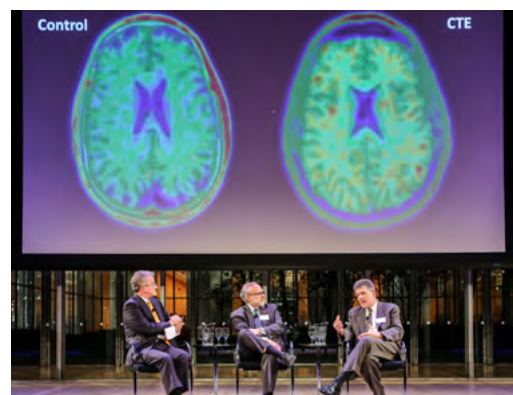
Dr. Sam Gandy is Mount Sinai Endowed Chair of Alzheimer's Disease Research, Professor of Neurology and Psychiatry and Director of the Center for Cognitive Health and NFL Neurological Care. His expertise includes amyloid metabolism.

Dr. Robert Stern is Professor of Neurology, Neurosurgery, and Anatomy & Neurobiology at Boston University School of Medicine. He also directs the Clinical Core of the BU Alzheimer's Disease and CTE Center. His research focuses on the long-term effects of repetitive head impacts in athletes.

Award-winning CBS 2 Medical Reporter Dr. Max Gomez moderated and expertly charted a path through a complex and provocative discussion exploring the intersections and divergences between Alzheimer's, CTE, and TBI.

Dr. Stern began by articulating the differences between Alzheimer's and CTE. Both are progressive diseases that can lead to dementia. However, unlike Alzheimer's, CTE has a specific risk factor: "a history of getting your head hit over and over again." According to Dr. Stern, CTE research remains in "toddlerhood," but steps are underway to "exploit the techniques" used to diagnose Alzheimer's in order to diagnose CTE in living patients.

Dr. Gandy's current work involves developing a visual biomarker for CTE in living athletes and soldiers. "One of the attractive things about studying TBI," he said, "is that we know when the injury happens," so doctors can develop ways to target the pathology almost immediately. On the issue of advancing the science, Dr. Gandy drew a comparison "to the way the Alzheimer's



Moderator Dr. Max Gomez and panelists Dr. Robert Stern and Dr. Sam Gandy discuss the differences between two brain imaging scans; the one on the right shows hallmarks of CTE.

field moved forward," namely through Alzheimer's research centers that continually examine and characterize patients.

The panel concluded with Dr. Gomez asking a question that brought a sometimes-clinical discussion to the concern of every parent in the room: "Would you let your kids play football?" Both panelists responded in the negative, but, as is often the case when discussing TBI, there were no easy answers.

The night drew to a close with CaringKind's Executive Vice President, Director of Programs & Services Jed A. Levine sharing some of CaringKind's exciting initiatives. Among them is UsAgainstAlzheimer's, a grassroots "mobilization of forces" from all walks of life pressing for urgency from government, industry, and the scientific community. Mr. Levine ended the evening with an impassioned plea for the audience to keep the pressure on their elected officials by asking them directly, "What are you doing about Alzheimer's and dementia?"

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, nonprofit and human rights organizations.



From Left: Dr. Max Gomez; Dr. Robert Stern; Dr. Sam Gandy; Lou-Ellen Barkan; Jed A. Levine; John Latham, CaringKind Board Co-Chair

A Big Step Forward



ANN WYATT

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As we have discussed in past issues, since 2012, CaringKind has been working with three New York City nursing homes (Cobble Hill Health Center in Brooklyn and Isabella Geriatric Center and The New Jewish Home in Manhattan) to implement a model of palliative care developed by the Beatitudes Campus in Phoenix, Arizona, for people with dementia. This comfort-focused approach which Beatitudes developed is known as Comfort Matters®, and now includes an official designation process for those homes that meet its standards for high-quality dementia care.

We are enormously proud to report that this past November, all three of our nursing home partners have achieved accreditation for their pilot project dementia units, in addition to a second unit at Isabella and a third unit scheduled for an accreditation visit in March. CaringKind staff participated in the accreditation visits by Comfort Matters and can confirm that what we observed,

and what we heard from interviews with all levels of staff and with families, is everything we hoped for; these units are truly transformed.

As part of our work with these three homes, we recently published *Palliative Care for People with Dementia: Why Comfort Matters in Long-Term Care* (available for free download at caringkindnyc.org/palliativecare), which describes how the homes went about implementing this approach. Copies of this publication have been sent to every nursing home in New York State, and have also been shared with nursing homes, organizations, and individuals all across the country.

We are also pleased to share that other homes in the New York metropolitan area have expressed interest in this approach as well, including NYC Health + Hospitals/Coler on Roosevelt Island. Coler has been working on its own to implement some of the Comfort Matters practices, and in December it invited staff from our three homes to share their experiences at a conference. A dozen staff from Cobble Hill, Isabella, and The New Jewish Home participated, and staff and a family member from Coler presented as well. Among the nearly 100 attendees were representatives from other H+H homes (Susan Smith McKinney, Gouverneur Health and Henry J. Carter Specialty Hospital and Nursing Facility). Below are photos from the Coler conference.

It has been an enormous privilege to help in bringing this truly excellent model of care to New York, and we are deeply grateful to our funders, who not only provided their support, but have also been as excited and moved by this work as we are: the Fan Fox and Leslie R. Samuels Foundation, Inc.; Lucius N. Littauer Foundation, Inc.; The Mayday Fund; The Milbank Foundation for Rehabilitation; PARC Foundation; United Hospital Fund; The John A. Hartford Foundation; and additional funding from the Altman Foundation to support a related capacity-building component. Additional contributions came from 1199 SEIU Training & Employment Fund & The Greater New York Education Fund; Caccappolo Family Fund; Daniel and Nancy Finke; Matthew Furman and Judy Hecker Furman; Benjamin Jenkins; Sharon Kilmer; and CaringKind and its Junior Committee have also allocated funds to this project.

In the months ahead, we look forward to sharing what we have learned with other homes throughout the area, as well as with the families and friends of people with advanced dementia, so that this approach is adopted far more widely. We have provided educational sessions here at CaringKind, and have done presentations at a number of conferences, including one for the NYC Nursing Home Ombudsman Program.



CaringKind and our three partner nursing homes met with staff from Coler Hospital and other H+H homes to share our successes in improving the quality of care for people with dementia.

What Makes the MedicAlert® NYC Wanderer's Safety Program Unique?



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Part of our mission statement is to create, deliver, and promote comprehensive and compassionate care and support services for individuals and families affected by Alzheimer's disease and related dementias. Since there has been an increase in the number of persons in the baby boomer generation diagnosed with Alzheimer's disease and other related dementias, there has also been an increase in the number of people who wander and become lost.

Although some individuals can get lost during the early stage of the disease, it is during the middle stage of the disease when memory and cognitive problems make it increasingly difficult for the person diagnosed to organize one's thoughts, leading to disorientation and a greater likelihood for wandering.

At CaringKind we have created a simple and unique low-tech program called MedicAlert® NYC Wanderer's Safety Program for persons who wander near or far. Persons with Alzheimer's disease or a related dementia who enroll in the program receive identification jewelry engraved with their name and medical information and the 24-hour MedicAlert Emergency Hotline number (800-625-3780) for emergency responders to call when the person is found. Caregivers are also eligible to enroll in the program and receive their own identification jewelry that, in the event they experience their own medical emergency, indicates to first

responders that they are a caregiver for a person with dementia. The Wanderer's Safety Program will then contact the people the caregiver has designated to assist with care while the caregiver recovers. This program gives caregivers some peace of mind.

You might wonder how exactly the program works. If and when a person goes missing, we ask the person who is reporting the incident to search the immediate area. If the person is not found within minutes then we advise them to dial 911. Do not leave the site where the person went missing. When the police arrive, be prepared to give a description of the person, including their physical characteristics and clothing description. If you have a current picture of the missing person on your phone show it to the police officer. This will help with their search efforts.

Once the police have completed canvassing the area they will call the MedicAlert Emergency Hotline and provide a detailed missing person incident report. An incident report is generated and automatically sent to the MedicAlert NYC Wanderer's Safety Program staff, who then follow up with the caregivers and assist the police department in locating the missing person. We activate a missing person's bulletin, which is sent to 258 recipients, including local New York City Police, hospitals, and other emergency responders throughout the five boroughs and neighboring counties. We also send the missing person's information to the media, if the family has given permission.

During this stressful and emotional situation, the Wanderer's Safety Program team will provide the caregiver with necessary support, deep understanding,

and a compassionate ear until the missing person is found. We listen carefully to what the caregiver has to say, and remind them to remain hydrated and take their medications. If necessary, we will contact other family and friends on their behalf so they don't have to feel alone during this traumatic time.

If you are a donor who is contemplating where you would like to make a difference, the Wanderer's Safety Program is without a doubt a program that has proven to be successful.

On average we work on five to seven missing cases a week. We enroll approximately 130 people into our program on a monthly basis. We have a 99 percent success rate in finding persons during a missing person incident throughout the five boroughs. And after every closed case, we provide ongoing support to the caregiver. The families are referred to our Social Work Services and Helpline departments so they can provide the necessary resources to the caregivers and help them create a safe long-term care plan.

I remember a caregiver by the name Maria saying, "I can only imagine what could have happened to Mom if your program did not exist. Please pass along my extreme gratitude to all involved in helping her return safely. Your organization and the caring people who staff it are not only a vital part of my peace of mind, but you offer hope to many other caregivers as well."

You can go to caringkindnyc.org/wandersafety to read more about the MedicAlert NYC Wanderer's Safety Program. If you have any questions, please call 646-744-2900.

Engaging People with Dementia at NYC's Cultural Institutions



MEREDITH WONG

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In creating the connect2culture® program, CaringKind recognizes how invaluable arts and cultural programs are to helping people with dementia and their caregivers remain engaged with each other and with their environment. The program offers training to educators at cultural institutions who are interested in creating and leading multisensory gallery and art-making experiences for these populations. It also provides training for general museum staff to ensure a positive experience from every interaction. So, what does this mean for the program participants?

I was asked to train a group of museum educators to create a program for this audience in its permanent collection and special exhibitions. After the training, the educators had a better understanding of how to adjust their communication and manner to suit the needs and abilities of their program participants who were experiencing different stages of dementia. Most educators teaching in cultural institutions want to connect with the emotional, social, and physical abilities of the individuals in their program. Once that connection is made, the educator is able to build trust, even for a short period, in order to take the participants on a journey, using the collections and exhibitions to tell stories and inspire memories.

Seated in front of a work of art, the museum educator asks the group to take a few minutes to just look at it, perhaps to notice patterns, textures, colors, or

materials. Allowing for a bit more time to take in the artwork, the educator circulates around the group, talking with some of the individuals, asking questions like, "What do you see?" confirming that, "yes, the green of the grass is bright." Caregivers also appreciate the time to look themselves, taking a moment to talk with the person they're with about connections they're making. This unique social interaction isn't a discussion about taking medication or wearing a jacket that isn't appropriate for the cold weather. It's about something outside of their immediate situation, an experience they can discover together. They're in a place where both of their voices matter and are appreciated.

Beyond just looking and talking, these programs use multisensory experiences to encourage connections through art and other types of collections, opening doors to words and activities that may not have been accessed otherwise. Smelling spices kept in the ornate containers on display may remind someone about celebrating the Sabbath as a child with their family. Sliding a swatch of rich velvet in between their fingers while looking at a portrait of a person dressed in their fine velvet might remind a participant of wearing a favorite velvet holiday dress.

This is how the storytelling starts. Some botanic gardens, science, history, and art museums in the boroughs already

have regularly scheduled programs that have been created in partnership with connect2culture. With the program's training, museum educators learn how to create enjoyable, engaging, and nonjudgmental environments and programs for their participants. Connect2culture actively seeks and develops relationships with New York City cultural organizations and institutions to make sure residents in all five boroughs have access to this type of program. It supports these programs holistically and enthusiastically, from preparing the staff to welcome these visitors to helping to develop audiences in their communities.

In addition to my expertise in developing cultural programs for people with dementia and their caregivers, I can also bring CaringKind's resources and expertise to institution staff and program participants. Support of this program through your donation says that you believe in the value of cultural programs that strengthen the abilities of people with dementia, engaging them through special interests, and creating an opportunity for caregivers to become involved in creative and new experiences. Educators trained by CaringKind's connect2culture staff are invested in offering a high-quality, engaging, and enjoyable experience, capitalizing on their participants' abilities and their institution's collections.



Photo by Jesse Chan-Norris

Why Donors Should Invest in Our Trainings



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CaringKind recognizes that in the absence of a cure or effective treatment for the majority of dementia-related diseases, the most significant investment we can make is in the human resource. Although medical research has made strides in better understanding the myriad causes that precipitate dementia symptoms, the vast majority of seniors diagnosed with dementia have Alzheimer's disease, which, for the moment, has no cure and a very slow progression. The goal of CaringKind's Training program is to ensure that professional and family caregivers are prepared to care for a person with dementia throughout the longevity of their disease, which in many cases can span more than ten years.

Our nationally recognized training models seek to enhance knowledge, develop skills, and provide support. Caregivers often enter training with misinformation on the causes of dementia and have unrealistic expectations of those they care for. Both our professional and family/friends training programs spend a significant amount of time on the causes and progression of dementia-related diseases. Our Dementia Care Trainers ensure that information is provided in a didactic manner so that each group attains an individualized learning experience to relate that knowledge of dementia to the person they care for.

By providing family/friend caregivers with a better understanding of the stages

a person with dementia may experience, we create the opportunity for them to be prepared for the types of care and support the person with dementia will require as they progress through their illness. Creating an informed plan of care and anticipating the types of financial and medical decisions that will need to take place become more feasible. Because of the nature of progressive dementias and the lack of curative treatments, it is crucial that caregivers understand the disease and have an opportunity to think of the types of financial and healthcare decisions they will need to tackle later on.

**No one person
can provide care
to someone
with dementia on
a 24-hour basis.**

Family members and friends supporting a person with cognitive impairment require continued access to information and supportive services throughout the long course of the illness. CaringKind offers a ten-hour, interactive program designed to improve the quality of life of caregivers and the person with dementia. Topics covered include understanding dementia, effective communication, all behaviors having meaning, safety in the home, caring for the caregiver, and designing strength-based activities.

No one person can provide care to someone with dementia on a 24-hour basis. As people progress through their

illness, family members and friends find it necessary to incorporate professional caregivers to support the person with dementia's advancing needs. As the person's needs progress, the assistance of a paid caregiver often becomes a necessity. Professional caregivers may receive one or two hours of instruction as part of their licensing or certification process. Most professional caregivers are exposed to the challenges of caring for someone with dementia while on the job and problem-solve as best they can. This trial-and-error method of learning creates a tremendous amount of stress on both the person with the impairment and the caregiver attempting to establish a relationship. At CaringKind we realize the impact that proper training has on the caregiving system as a whole. We provide paid caregivers with the opportunity to register for our six-week, nationally recognized program that aims to help paid caregivers provide the highest quality of care to persons with dementia. This 45-hour program utilizes a person-centered approach to dementia care, which emphasizes the importance of an individual's needs, preferences, and strengths. Paid caregivers who are prepared to care for a person with dementia experience higher job satisfaction and are less likely to seek other employment or leave the caregiving field. In addition, training reduces stress and affords the paid caregiver the opportunity to better understand how to communicate with their client and establish better relationships.

It is crucial that we invest in developing and training the human resource type of treatment available to people with dementia because, currently, it is the only effective type of care we have.

Education Today for a Better Tomorrow



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According to estimates, there are over five million individuals in the U.S. over the age of 65 with Alzheimer's disease. If no cure or treatment is found, that number will increase to approximately 14 million by 2050. Unfortunately, these frightening statistics represent more than numbers. Each number represents a person with the disease, perhaps your spouse or family member, a friend, or your coworker. So what can you do about it? While there is currently no prevention or cure for a type of dementia like Alzheimer's disease, we do know that early detection is key in preparing for the future. In fact, in the majority of Alzheimer's cases, family members, friends, or neighbors are the first to notice the warning signs. Knowing what to do when the warning signs start and where to go for help is the hallmark of our education courses. Investing your time to learn about the disease now will prepare you with information for the future.

Learning about Alzheimer's disease or another type of dementia doesn't stop at knowing the warning signs. What if the person you are providing care for is past the point of warning signs? What's special about our education courses at CaringKind is that they are uniquely structured to provide informal and professional caregivers from diverse fields of practice with crucial information on how to support a person with dementia (PWD) at any stage in the disease. Caregivers

and professionals who are working with a PWD describe CaringKind's education seminars as being "an eye-opener," no matter where they are in the caregiving journey. Oftentimes, those who attend the seminars share comments such as "I feel like now I understand why [he or she] is behaving [or communicating] differently" or "This information will help me support my [family member or friend] in a better way." Learning about changes in the brain, the diagnostic process, or how to communicate with someone who is living with the disease are examples of priceless information that advance a caregiver's skillset and preparedness.

CaringKind's educational seminars reveal that Alzheimer's disease or another cause of dementia is more complicated than just changes with memory – the disease changes a person's cognition, behavior, and physical functioning too. As a caregiver, if your main concern is about cognition, the way someone behaves, or how to maintain safe physical functioning, all of the seminars are structured to encourage you to utilize self-direction. A caregiver has the option to attend an education seminar as many times as he or she feels is necessary, at no charge. Professionals are also encouraged to attend our free Understanding Dementia for Professionals Seminar, with the option to apply for continuing education units for a fee. Caregivers often wonder: "How does the disease change a person's

behavior?" or "How can I support [the person I'm caring for] with bill paying and healthcare decisions?" And perhaps one of the most common questions, "What do I do next?" To answer these questions and provide further direction, CaringKind's educational seminars are expanding throughout the city, with offerings such as our Understanding Dementia Seminar: What You Need to Know and Where to Go, Legal and Financial Seminar, Medicaid Home Care Seminar: A Practical Guide to the System, and Placing Your Relative in a Nursing Home, as well as our Monthly Education Meeting, which covers a new topic derived from issues we hear about from caregivers and professionals each month.

CaringKind's educational seminars provide invaluable knowledge and support for caregivers and professionals. The information can improve quality of life for caregivers, and the person they are caring for. To learn more about how an education seminar can help you and which meetings are closest to you, contact our 24-hour Helpline at 646-744-2900, visit our website at caringkindnyc.org/education, or turn to pages 32-33 to view our education calendar.

Celebrating Our Differences



NIURQUI "NIKKI" MARIANO

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You might come across our African American Outreach Manager at a church in Harlem or our Latino Outreach Manager in a Bronx senior center. Don't be surprised to bump into our Chinese Outreach Manager at a Queens library in Flushing, or if you're a healthcare provider you might sit in on one of my next presentations. With MetroCard in hand, our Diversity and Outreach team travels throughout the five boroughs with one common goal: to educate the community about Alzheimer's disease and about CaringKind's free programs and services.

In comparison to non-Hispanic whites, African Americans and Latinos are more likely to develop Alzheimer's disease, but are less likely to get an early diagnosis, which delays treatment and care planning. Language barriers, cultural beliefs, stigmas, and myths associated with the disease can oftentimes prevent caregivers from reaching out for help. This is why we don't sit and wait for you to reach out to us; we bring awareness about our services to you, in your own familiar community.

CaringKind recognizes that we serve a city of great diversity. Each group has its own unique needs, and our professional staff is representative of the city we serve. Our team is multilingual and can provide presentations, workshops, and trainings not only in English, but also in Spanish,



From left: Jed A. Levine and Niurqui Mariano are joined by Elizabeth Berberian, New York State Department of Health; Julio Gonzalez, R.A.I.N.; and Juan Gabriel DeJesus, VNS, at the 2nd Annual Hispanic Alzheimer's Conference reception hosted at CaringKind on November 18th.

Mandarin, and Cantonese. Our Spanish and Chinese newsletters combined are mailed to over 7,000 homes. Our annual Chinese caregiver's trip is well attended and provides caregivers with an opportunity to connect with other families who share similar experiences caring for a relative with Alzheimer's or dementia. For six years in a row the African American Outreach program and the Healthcare Outreach program have partnered with Empire State Medical Association to educate African American physicians about Alzheimer's disease and our services. Our Chinese Outreach program and Healthcare Outreach program have partnered with VNS Asian Outreach to educate Asian physicians.

Over the years we've partnered with faith-based organizations, medical associations, farmers markets, local community agencies, community

hospitals, and other nonprofits. These strong partnerships aid us in deepening our ties to the community and in expanding our outreach efforts, because, just like the caregivers we serve, we too can't do this alone.

New York City is a big city and we still have a lot of work to do. I look forward to the day I no longer hear caregivers say "I wish I would've known about your services when I cared for my loved one." With your help this can one day change. Every dollar you donate to CaringKind stays here in New York City and helps expand our outreach efforts. They say the first step towards change is awareness. Help us continue to spread awareness about this devastating disease; it's our only hope for change and making more New Yorkers aware of the free resources and services at CaringKind.

Caregivers stopped by the National Memorial Arch at the Valley Forge National Historical Park in Pennsylvania during this year's annual Chinese caregiver's trip on September 28th.



Brain Health Day

Brain Health Day 2016 was organized by CaringKind, the Asian Health & Social Service Council (AHSSC) and the Chinese Consolidated Benevolent Association (CCBA). The event, held on November 9th at the CCBA in Chinatown, was very successful, with approximately 350 seniors and caregivers from all five boroughs in attendance. Nineteen organizations sponsored the event, and a total of 30 community healthcare and social service agencies participated and introduced their services during the event. The goals of Brain Health Day were to raise awareness of Alzheimer's disease and related dementias, to introduce available

community healthcare and social service resources to the senior members and caregivers, to promote CaringKind's programs and services and extend CaringKind's reach in the Chinese community, and to enhance the well-being of seniors in the Chinese community.

A health workshop about brain function and Alzheimer's disease was conducted by Weijing Shi, CaringKind's Manager of Chinese Outreach, and Andrew Wu, a SUNY Downstate medical student.



Another educational workshop about Legal & Financial Planning including the importance of advance directives was led by Pauline Yeung of Grimaldi & Yeung LLP, an attorney specializing in elder law, as well as the Secretary of CaringKind's Board of Directors. Vendor educational games, a raffle, entertainment, and healthy food also were enjoyed.



Left Photo: From left: Lucia Sau Chan, Mount Sinai Beth Israel; Weijing Shi, CaringKind; Pauline Yeung-Ha, Grimaldi & Yeung LLP and Secretary of the CaringKind Board of Directors; Shirley Huang, Royal Care NYC; and Anderson Dong, Healthfirst; at Brain Health Day. Center Photo: Roberto Reyes (right), CaringKind Manager of Latino Outreach, is joined by Stephan Giordani (left), Carmen Pastor (center left) and Mary Theresa Vasquez (center right), all of Fuerza Contra Alzheimer, at the 2nd Annual National Hispanic Alzheimer's Conference. Right Photo: Jed A. Levine, Executive Vice President, Director of Programs & Services of CaringKind, and Carmen Pastor, President of Fuerza Contra Alzheimer, at a pre-conference reception hosted at CaringKind on November 18th.

Hispanic Conference on Alzheimer's

On November 19th, CaringKind partnered with Fuerza Contra Alzheimer to bring the 2nd Annual National Hispanic Alzheimer's Conference to New York City. The free conference was held at the Brookdale Center for Healthy Aging in the heart of "El Barrio," and brought together doctors distinguished in various disciplines that work directly in the Latino community. The physicians and researchers covered the latest in patient and caregiver care currently taking place.

The purpose was to inform, educate, and train all who are involved in the care of persons with Alzheimer's disease. The conference provided a unique forum for the elderly and caregivers to discuss important issues on a one-on-one basis, offering a great opportunity to network with knowledgeable experts and those in need.

Among some of the distinguished speakers and guests were Elizabeth Berberian, New

York State Health Department for the Aging; keynote speaker José Luchsinger, M.D., MPH, Columbia University Medical Center; and international panel moderator Diana Morales, M.D., MPH, Assistant Professor and Associate Director at the School of Behavioral & Brain Science of CAIMED, Ponce, Puerto Rico.

2016 TCS New York City Marathon

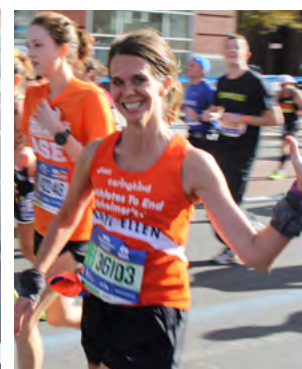


CANDACE DOUGLAS

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Just after 5 a.m. on November 6th, while most of New York City was still in bed, 100 members of team Athletes to End Alzheimer's® (ATEA) were making their last-minute preparations en route to join their fellow teammates, ready to take on the streets of all five boroughs for the 2016 TCS NYC Marathon. Excitement and anxiety were palpable in the air as they gathered for the last time before joining 50,000 fellow runners in Staten Island to start what is often called "New York City's largest block party." Before the end of this beautiful fall day, they would cross the finish line in Central Park, raise over \$400,000 to support CaringKind's programs and services, and become permanent members of CaringKind's ATEA community.

The TCS NYC Marathon is one of the premier marathons in the world, with this year's race breaking records for the largest number of marathon finishers. For some of the ATEA teammates, this would be an opportunity to hit a personal record on a well-known and beloved course, while for others this would be their chance to join that most coveted



club: marathon finishers. Traveling from as far as the Netherlands, and as close as down the block from the Central Park finish line, all team members ran with a common motivation. They wanted to raise their voices and their running feet for the Alzheimer's cause and in honor of the unique sacrifices made by caregivers daily.

When our athletes donned our signature orange singlets and selected to run on behalf of CaringKind, they did so because they embraced our mission and knew that being an Athlete to End Alzheimer's went far beyond any one race on any one day. Lacing up their sneakers to start the race, they may have been transported to the first time they heard that someone they cared about had been diagnosed with dementia, cognizant of the journey ahead.

Staring over the vast expanse of the Verrazano Bridge at the start in Staten Island, the runners could have recalled how far and wide the effect of that diagnosis spread across their family. Greeting the diverse faces of the cheering onlookers in Brooklyn, they may have relived the importance of being supported throughout the Alzheimer's journey by

their friends, family, and organizations like CaringKind, which, for over 30 years, has worked tirelessly as the expert of dementia caregiving for families in need.

When the runners caught a breath just past the halfway point in Queens, they could acknowledge that this race to end Alzheimer's disease is also still ongoing. But just like the nutrition coursing through their bodies to refuel them and keep them moving forward, in the absence of a prevention or treatment, good care is the best medicine for this devastating disease. Their fundraising efforts helped to provide more access to good care for themselves and fellow New Yorkers who turn to CaringKind every day. Briefly popping into the Bronx to complete the tour of all five boroughs, the ATEA marathoners could acknowledge that the journey could look different for every family and every caregiver affected by this disease, but the need to be supported is universal.

And when the runners finally crossed the finish line in Manhattan, they did so knowing that they were really just starting their "leg" in the effort to destigmatize this disease and provide support to everyone who has been, is, or will be touched by a dementia diagnosis. Because, that is what it really means to be an Athlete to End Alzheimer's.

Interested in participating in the TCS NYC Marathon or another ATEA event in 2017? Visit caringkindnyc.org/athletes.



A Compassionate Mission

By Brittany Krygowski
Junior Committee Vice President

Alzheimer's is known, for all intents and purposes, as an "old person's disease." So it may seem surprising that the members of the CaringKind Junior Committee, virtually all of whom are under age 40, eagerly come together to raise funds to support research and programs benefiting people affected by the disease – those diagnosed, their families, and their caregivers alike.

Some five million Americans live with Alzheimer's today and, according to certain statistics, that number is projected to triple by 2050. For those 20- and 30-somethings who have been fortunate enough not to bear witness to the devastating effects of the disease, that number may seem abstract, something they inherently understand they should care about, but the magnitude and significance of which they struggle to grasp. And who can blame them? With so much strife and turmoil in the world today, a young person can hardly be faulted for overlooking a disease whose eventuality seems as far in the future as

a life without computers or cell phones is in the past.

But many members of the Junior Committee *have* been touched by Alzheimer's. In fact, most of us are only one degree of separation from Alzheimer's – ask around the room at any of our monthly meetings and you will hear stories of grandparents, parents, aunts, and uncles whose battles with the disease have inspired our young members to continue the fight in their honor. However, the fight against Alzheimer's is about more than the legacy of those passed. As young donors, our funds aren't just revenge against the disease for the spoils of the past. They are an investment in the future, in our future as individuals and as a community.

Our generation has been accused of being self-centered, but you wouldn't know it from our members' fervent fundraising and passionate participation in events. Though we allocated a portion of our funds last year to research, most of the money we raised went to helping endow some of CaringKind's programs, which benefit those currently affected by Alzheimer's who need assistance *today*. If we envision our time, effort, and money as an investment in the future, how do we reconcile that with funding programs that seemingly exist for the present? Simply

put, we understand that the war must be waged on all fronts. As a long-term strategy, we must hedge our investment in the eradication of the disease through prevention and a cure with an investment in the care of those struggling with the disease in the here and now. We can neither neglect to advocate for legislation to support Alzheimer's research in the future, nor can we neglect to spend time with those diagnosed who need care and compassion.

For those of us who are children, grandchildren, nieces, and nephews of Alzheimer's sufferers, it's a mission driven as much by compassion and empathy as it is by utility. We understand both the financial detriment to families and the emotional turmoil of watching a loved one's condition deteriorate. We know the confusion and fear that a diagnosis can bring. We are proud to dedicate our time and energy to CaringKind, an organization that provides desperately needed resources to New Yorkers suffering from dementia and their caregivers. Because we, the members of the Junior Committee, come from many different places and backgrounds and are many different things: some of us are the ambitious kind, some of us are the generous kind, most of us are the busy kind. But all of us are the CaringKind.

RIDE TO REMEMBER

Join us for a spin class! Sign up to do the ride yourself, or sign up with a team to spin together!

caringkind

Junior Committee.

RIDE TO REMEMBER

caringkind The Heart of
Alzheimer's Caregiving
Junior Committee.



Swerve Fitness
21 W 46th St, New York, NY 10036
Thursday, April 6 - 7:30 pm

Contact: Lauren Longobardi at LMLongobardi@gmail.com
Register here: www.caringkindnyc.org/juniorcommittee

**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
Carter Burden/Leonard Covello
Senior Program
The Elly & Brochie Kleinman OHEL
Heights & Hills
Queens Community House
Regional Family Center
Riverstone Senior Life Services
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:

February 14	5:30 - 7:30 p.m.	Manhattan
February 15	1:00 - 3:00 p.m.	Brooklyn
February 15	5:30 - 7:30 p.m.	Manhattan

March 2	3:30 - 5:30 p.m.	Queens
March 10	12:00 - 2:00 p.m.	Manhattan
March 14	5:30 - 7:30 p.m.	Manhattan
March 15	5:30 - 7:30 p.m.	Manhattan
March 15	6:00 - 8:00 p.m.	Brooklyn
March 22	5:30 - 7:00 p.m.	Brooklyn NEW

April 5	6:00 - 8:00 p.m.	Queens
April 11	5:30 - 7:30 p.m.	Manhattan
April 14	12:00 - 2:00 p.m.	Manhattan
April 19	1:00 - 3:00 p.m.	Brooklyn
April 19	5:30 - 7:30 p.m.	Manhattan

Upcoming Date Just for Professionals:

March 8	3:00 - 5:00 p.m.	Manhattan
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Upcoming Date in Spanish:

March 10	12:00 - 2:00 p.m.	Manhattan East Harlem
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Upcoming Dates in Chinese:

February 25	2:30 - 4:30 p.m. (Mandarin)	Queens
April 22	10:30 a.m. - 12:30 p.m. (Cantonese)	Manhattan

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 Date in English:

Manhattan	
March 21	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 in English:

March 2	5:30 - 7:00 p.m.	Manhattan
April 6	5:30 - 7:00 p.m.	Manhattan

Upcoming Date in Spanish:

April 19	2:00 - 3:30 p.m.	The Bronx NEW
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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 in English:

Tuesdays	February 14, 21, 28 & March 7	5:30 - 8:00 p.m.	Manhattan
Mondays	February 27 & March 6, 13, 20	12:00 - 2:30 p.m.	Manhattan
Wednesdays	March 1, 8, 15, 22	5:30 - 8:00 p.m.	Manhattan

Upcoming Series Dates in Spanish: Please call the 24-hour Helpline.

Monthly Education Meetings

Meeting topics change monthly based on questions received from caregivers.

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

February 13

Family Conflicts in Caregiving

- Explore common reasons for conflict.
- Discuss strategies for effective communication.
- Learn about resources and coping mechanisms for managing conflict.

Speaker: Anne M. Foerg, LMSW, CaringKind; Rita Greenfield, LMSW, CaringKind

March 13

Dementia and Nutrition: Improving Mealtime

- Uncover nutritional strategies to enhance a person with dementia's well-being.
- Learn how to support challenging dietary issues caused by dementia.
- Find out how adaptive equipment or changes in meals can facilitate mealtime.

Speaker: Lisa Zulig, MS, RDN, CSG, CDN, Director of Nutrition Services at God's Love We Deliver

April 10

Managing Challenging Behaviors

- Redefine the meaning of behavior.
- Understand causes of behavioral changes.
- Formulate strategies to adapt and adjust responses to behaviors.

Speaker: Marilucy Lopes, LMSW, CaringKind

Legal & Financial Seminar

An attorney specializing in elder law discusses important topics Alzheimer's and dementia 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 in English:

Manhattan

February 23 12:00 - 1:30 p.m.

March 6 12:00 - 1:30 p.m.

March 20 5:30 - 7:00 p.m.

March 23 5:30 - 7:00 p.m.

April 3 12:00 - 1:30 p.m.

April 17 5:30 - 7:00 p.m.

April 27 5:30 - 7:00 p.m.

Brooklyn **NEW**

April 12 5:30 - 7:00 p.m.

Queens **NEW**

March 15 3:00 - 4:30 p.m.

Upcoming Date in Spanish: **NEW**

Bronx

March 8 2:00 - 3:30 p.m.

Upcoming Date in Mandarin:

Manhattan

March 16 1:30 - 3:30 p.m.

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

NEW & EXPANDED Programs

caringkind The Heart of
Alzheimer's Caregiving

Social Work Services

Added new staff to our Social Work Services department who will provide individuals and families with personalized support, information and guidance including care planning, counseling and advocacy.

Expanded Education Programs

Our Education Manager is expanding our education offerings in Manhattan and the boroughs, creating new topics and responding to the needs of caregivers across NYC.

New Helpline Specialists

We now have enhanced capacity in the CaringKind office to respond to more callers with information, education and support.

connect2culture®

Works with art museums and other cultural institutions to provide programming for persons with dementia and their family caregivers.

Respite Specialist

Social Worker on our 24-hour Helpline provides guidance to families in need of a break from caregiving, referring to community respite programs and access to short-term financial assistance.

Brooklyn

Dementia Care Specialist provides outreach and support to families in Brooklyn.

Queens

Outreach Social Worker provides education and support to families in Queens.

The Bronx

Outreach Social Worker provides education and support to families in the Bronx.

Staten Island

Outreach Social Worker provides education and support to families in Staten Island.

caringkind chronicles

Writer: Jennifer Camper Artist: Ivan Velez

Episode 1

CRISTINA



Mom

ROBERT



Dad

ANGIE



Daughter

MICHAEL



Son

ESTELLA



Grandmother



TO BE CONTINUED...

Mild forgetfulness can be a normal part of the aging process. But when memory problems begin to seriously affect daily life, they could be early signs of Alzheimer's disease or another dementia. For more information, call the 24-hour CaringKind Helpline at 646-744-2900 or go to caringkindnyc.org.



The Heart of Alzheimer's Caregiving

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

CHANGE SERVICE REQUESTED
caringkindnyc.org

646 744 2900 — 24-hour Helpline

NON-PROFIT ORG.

U.S. POSTAGE

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ST. JOSEPH, MI

PERMIT No. 244

Programs and Services

24-hour Helpline at 646-744-2900

Social Work Services

The Harry and Jeanette Weinberg Early Stage Center

Support Groups

MedicAlert® NYC Wanderer's Safety Program

Palliative and Residential Care Program

connect2culture®

Together We Care™

Education and Training

Understanding Dementia for Caregivers & Professionals

Dementia Care Training for Professionals

Monthly Education Meeting

Legal & Financial Seminar

Medicaid Home Care Seminar

Placing Your Relative in a Nursing Home

Family Caregiver Workshop