

caringkind

The Heart of Alzheimer's Caregiving



SUMMER 2018

- *Join us at one of our four CaringKind Alzheimer's Walks this fall. For more information, please visit www.caringkindnyc.org/walk or see the back cover.*

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Dear Readers,

In 1990, George H.W. Bush was President. The cost of a postage stamp was 25 cents. The New York Yankees finished seventh in the American League East with a dismal record of 65 – 97. Best song of the year went to Bette Midler for “The Wind Beneath My Wings.” The number of murders in New York City reached a record high. And I began my career as a staff member at CaringKind.

While a lot has changed in our nation and city, one thing remains a constant: Alzheimer’s – a disease with no cure, no prevention and no disease modifying treatments – continues to take an unprecedented toll on those who have the disease and their family caregivers.

In this, my inaugural column as the new President and CEO, I promise that something else will never change: the commitment of CaringKind to provide anyone facing a dementia diagnosis with the help and care they need, when they need it. The dedicated and compassionate Alzheimer’s and dementia professionals who work here at 360 Lexington Avenue are wholeheartedly committed to CaringKind’s core mission. They will continue to work tirelessly to create and deliver comprehensive and effective programs for any New Yorker who is affected by Alzheimer’s or a related dementia.

Over these past nearly 30 years, I have heard time and time again how important it is for people in our community to have a place to come where they are really understood, and where they can get guidance to help them navigate a very frightening landscape.

In fact, I just spoke to a caregiver who told me that before she came to CaringKind, she was feeling very alone and fearful. She had no idea how to cope with her husband’s unwanted and unanticipated diagnosis. The assistance and encouragement she received from

our staff gave her the strength and the will to deal with her new reality. She said, “I know now that I am not alone.” I never want to lose sight of this experience for the individuals and families who call us.

What sets CaringKind apart from any other organization is the vast number of unique programs and effective services we offer – and not just in Manhattan. The level of support we provide, our experience and depth of knowledge are simply unparalleled. We are New York’s dementia experts, the central address for Alzheimer’s and dementia care.

Serving New York City’s diverse communities will remain central to our mission as well. Our outreach programs for African Americans, Latinos, Chinese and LGBTQ people are geared to address issues specific to each community, reflecting the cultural nuances and languages appropriate to each.

CaringKind will continue to take advantage of our location in the cultural capital of the world and partner with some of the City’s premier arts and cultural institutions in our innovative program called connect2culture®. It’s a resource for families who want – and need – programs that normalize their experiences and give them a chance to engage in the kind of activities they enjoyed before dementia took over their lives.

Finally, I want to thank Lou-Ellen Barkan for her outstanding, innovative and creative leadership over these past 14



JED A. LEVINE
President & CEO
jlevine@caringkindnyc.org

years. So many of our advancements came directly from her brainstorming ideas. From our conference for chaplains and clergy, to our annual audiology conference and technology expos, each of her ideas has enhanced this organization and made it more responsive to those we serve. I am very glad that she has agreed to stay on and help with the continuity of leadership as I take on this larger role.

There is so much more to be done. Resting on our past success is not an option. And, moving forward, I hope I can rely on your support so that we can continue our critical work – bigger and better than ever.

P.S. I hope to see you at one of our four Walks this fall! For more information, check out the back cover of this newsletter or visit www.caringkindnyc.org/walk.



Dear Friends,

On July 1, 2018, I retired from my role as President and CEO of CaringKind. It has been my privilege to serve you for the past 14 years.



LOU-ELLEN BARKAN
Founding Director
lbarkan@caringkindnyc.org

I am deeply indebted to our talented, hard-working staff, now led by our new CEO, Jed A. Levine. Jed has been my partner since I walked through the door in March of 2004. I am confident that, under his leadership, CaringKind will continue to grow and prosper.

Thinking back to when I started, I was a neophyte in the fields of aging, Alzheimer's research, and dementia care. There was so much I didn't know. But thanks to staff and Board members, community partners, elected officials, clinicians and research scientists who gave so generously of their time and expertise, I learned fast. But something was missing until two things happened to fill in the gaps.

The first took place on a hot, summer night at a Tanglewood concert. My husband and I found our spot on the lawn, but when I realized I had left something in the car, I walked back to the parking lot. By the time I returned to the lawn, the concert had started and it was pitch black. I was completely lost. Within minutes, I was disoriented, scared, frustrated, and anxious. Just as another family took pity on me and invited me to share their picnic, I saw a familiar silhouette in the shadows, recognized my husband and we reconnected.

My reaction to the experience was unexpected. But, it was exactly what we hear from our clients as their world becomes an unstable, unsettled, and

frightening place. My experience gave me a new appreciation for what people with dementia are up against.

My second experience came a few months later at our annual Walk in Riverside Park – my first. Throughout the morning, as Jed introduced me to our families, I was thanked. I was hugged. I was kissed. I was even blessed. Everyone wanted me to know how grateful they were to CaringKind. I heard story after story of families in crisis who told me that they no longer felt alone and that CaringKind had, literally, saved their lives. Leaving the walk that day, I understood the real impact that CaringKind makes on the lives of families in crisis.

This lesson was reinforced in 2011 when my mother, who had dementia, came home to New York and, ironically, I became my own client. CaringKind's social workers were a godsend for me as they are for those we serve.

Today, fully informed and concerned about the rapidly growing population of aging Americans, I am struck by the absence of political focus on our issues and needs. After all, isn't aging something we all have in common? No matter how much we exercise, how well we eat, or how good our medical care, we will grow old. No matter our religion, race, culture, or economic status, if we are lucky, we will grow old. And when we do, our families will need precisely the programs and services that CaringKind provides.

Although I am stepping down as CEO after more than 14 years, I am staying on to contribute to the life-saving work we do every day. I hope that as more and more New Yorkers take advantage of CaringKind's programs, and as the word spreads, our community will take up these issues and work with us to ensure we have resources to grow. We must continue to advocate for the hundreds of thousands of New Yorkers who have dementia or who are caring for someone who does.

I know my time here has made a difference. I could not ask for more and I thank each of you for making it possible.

CaringKind's Second Annual Technology Fair



On April 16th and 17th, over 300 family and professional caregivers and 26 companies met at the intersection of technology and caregiving at our 2nd annual Technology Fair. Crispin Baynes, from the Aging2.0 New York Chapter, our partner for the event, kicked off the fair with a keynote address that brought us behind the scenes of what it takes to create some of today's most innovative products. He also highlighted the importance of caregivers' input in developing these products.

Jed A. Levine, CaringKind's President and CEO, added that technology often serves to complement CaringKind's "high touch" programs.

Products at the fair included mobile apps, websites, voice activated skills, virtual reality and much more. Dr. Max Gomez, CBS 2 Medical Reporter, visited the fair to sample some of the products and talk with caregivers. His report was aired on the evening news.

CaringKind would like to thank the following for their participation:

- Abely
- The Alzheimer's Store
- Alz You Need
- Antidote
- Audicus
- Balance: Alzheimer's Caregiving
- Bonbouton
- FallCall
- GreyMatters
- LifeShareCare
- MavenCare
- Music & Memory
- OneRecord
- Pixie Scientific
- Pop Doc
- RecallCue
- Rendever
- ReverCare
- SafeWander
- Sensors Call
- SilverBills
- Soundmind
- Timeless
- Timocco
- Tribute
- Wanderer's Safety Program

Please visit caringkindnyc.org/techfairvendors for a description of these companies and their products, as well as links to their websites.

We are excited to announce that we will once again include a Technology Expo at our annual CaringKind Alzheimer's Walk in Manhattan on Sunday, October 14th!



Pixie Scientific



Alz You Need



Super Aging with technology



RiverSpring Health's Balance App



(From left) Alison Becker (Aging 2.0), CaringKind staff: Marilucy Lopes, Jed A. Levine, and Ed Cisek, Marx Zamkow, Crispin Baynes (Aging 2.0)



Rendever



Music & Memory



Bonbouton



Jed A. Levine addresses the guests.



The Alzheimer's Store

Part One

What is dementia?

Dementia is an umbrella term used to describe a group of symptoms created by abnormal changes in the brain. Most diseases that precipitate the symptoms of dementia are generally progressive, meaning that the persons condition will worsen over time. Although Alzheimer's disease (AD) is the most common cause of dementia and accounts for approximately 70% of all dementia diagnoses, some other causes of dementia, however, are treatable or reversible. In these circumstances, symptoms of dementia may be attributable to other medical conditions such as endocrine abnormalities (thyroid disease or vitamin B12 deficiency), vision or hearing loss (resulting in withdrawal or isolation), kidney failure, depression, stress, medication side effects or medication interactions, infections such as urinary tract infection (UTI), strokes, or tumors.

Dementia is **not** a normal part of the aging process, but the result of a disease resulting in physical damage to brain cells. The symptoms of dementia vary from person to person, but generally involve changes severe enough to affect a person's daily life in at least some areas of: cognition (memory, thinking, language), behavior (mood, personality, social skills) and physical functioning (motor skills, personal care, visual field changes).

What is involved in receiving a diagnosis of dementia?

If a person is experiencing symptoms that affect his daily life, a diagnostic workup is recommended to determine the cause of those symptoms. The doctor, or team of doctors including a neurologist, psychiatrist, or psychologist will perform an evaluation which may include: family and medical history, a comprehensive physical exam, laboratory work, neuropsychological tests and scans of the head (MRI, PET or CT). A skilled team of doctors will analyze the

information and provide a diagnosis with approximately 90% or better accuracy.

Why is a diagnosis recommended?

Knowledge is power. The diagnostic process can rule out other conditions that may be treatable, such as the reversible causes previously mentioned. An accurate diagnosis is critical in determining the best type of treatment. Certain types of dementia may require different treatment modalities. People with dementia (PWDs) and their families benefit from having a diagnosis because it gives a name to the difficulties PWDs are experiencing. It may help them to cope with the daily challenges and provide a reason to make the most of each day. An early diagnosis also gives PWDs the opportunity to participate in planning for their own future in terms of legal and financial decisions and medical advance directives.



What are the risk factors for developing dementia?

While we cannot currently prevent dementia, there are certain things that may increase or decrease our **risk** of developing the condition. It's a subtle distinction but an important one in managing expectations of what is possible. There are some factors that have been associated with elevated dementia risk, including: age, family history, genetics, race/ethnicity, head trauma, heart and vascular health.

How does dementia progress?

Dementia usually progresses. Diseases that cause dementia progress over time

through early, middle, and late stage. In early stage someone may experience problems with short term memory loss, loss of initiative, problems with time and language difficulties. In the middle stage memory loss will increase, language comprehension will decrease, the person may have difficulty controlling their impulses. In the later stages, the person will require assistance to walk independently, have limited vocabulary, difficulties eating and require extensive physical care.

There is no "one-size-fits all" approach. Remember that every PWD is unique in terms of personality, personal history, and preferences, in addition to having different needs and abilities in early, middle, and late stages of the illness.

Can I still communicate with the person in the same way?

Communication will have to change. Changes in the brain of a person with dementia (PWD) will naturally effect the way they can communicate and interact with others. Caregivers often express frustration navigating these changes, not to mention coping with the emotional toll of losing the ability to communicate with their family member in the same way as before. It will take time to adjust to managing and shifting expectations. Caregivers often need significant support to release attachment to previous patterns of communication and develop a "go with the flow" attitude that is more beneficial for both the caregiver and the PWD.

Who can I go to for help?

No one can do this alone. As dementia progresses, caregivers will need to rely on a network of family, friends, and professionals for support. It is important for caregivers to be able to communicate their own needs and to ask for help. **As always, CaringKind's, 24-hour Helpline is available to provide caregivers with information and support at 646-744-2900, free of charge.**

Demystifying connect2culture® Training



MEREDITH WONG

Manager of connect2culture®
mwong@caringkindnyc.org

How many times have you gone to a museum where the staff understands the urgency of finding an accessible bathroom or helps you find the galleries or cafe? Trained staff know that if these requests can be met, their visitors will appreciate and likely remember their experience. Connect2culture believes that the key to creating spaces and programs that you can enjoy is an approach to visitor services that goes beyond training just the program staff. It extends to the security guard who is friendly and patient, or front-of-house staff who helps you and the person with dementia navigate the bag check and metal detector or the volunteer who guides you to a place to sit.

A connect2culture cultural partner organization participates in a training that is based on CaringKind's long established *Understanding Dementia for Professionals* presentation. It lays the ground work for understanding the disease's progression and teaches how cultural organizations can create a more inclusive and comfortable space. While the training encompasses information and practical skills for cultural environments, it also helps staff who are family caregivers by introducing them to communication skills they can use at home. In a recent connect2culture training with the Orpheus Chamber Orchestra, musicians and administrators found the information useful for performing in

dementia care communities as well as in their own caregiving. While this training is similar to *Understanding Dementia For Professionals*, it is tailored to the specific logistical challenges of each cultural space. For example, while a space may echo with cavernous rooms filled with activity and noise, dimly lit galleries of another are filled with ambient music or rapidly moving video. How might these organizations accommodate the needs of someone with dementia? With very different spaces, resources and collections, each institution are asked to consider these elements carefully.

When an organization decides to create a program for people with dementia and their care partners, the next step is for their program staff and facilitators to participate in a more comprehensive educator training. This training builds



Photo: Arts and Minds

on their understanding of the disease with engagement skills that will make the program enjoyable for participants and staff. Just as you learn to adjust the way you communicate and respond to the person in your care, the facilitator learns to do the same to create a positive experience of shared discovery and connection. It may be through integrating ceremonial musical instruments that

you can play while looking at images of temples where they may have been used. What words describe the kind of sound it makes? Or might you be looking at and feeling a piece of a soldier's uniform, and wonder what the badges or medals mean? What materials are they made of? What identifies the uniform as an officer's?

Knowing that the disease affects each person differently, the facilitator focuses on the strengths of their program participants by integrating different opportunities for participants to connect through sensory memories, for example, singing a familiar naval tune like *Anchors Aweigh* while sitting on the deck of an aircraft carrier or feeling moist soil in your hands as you pot an herb at the botanic garden. If someone has lost their sense of smell or taste, then other senses allow them to access the experience.

As the pool of cultural partners grows to include botanic gardens, performance and visual arts organizations, and history museums, connect2culture hopes that through understanding the effects of dementia on the whole community – friends, neighbors, family – the sensitivity to their needs for sensory and social stimulation will grow.



Smelling herbs along the garden path.
Photo: CaringKind



Photos: Lincoln Center

"To make **Lincoln Center Moments**, a free performance-based program designed for people with dementia and their caregivers, possible, CaringKind provided staff training, led focus groups and shared program design feedback throughout the development and rollout process. By engaging connect2culture for Training and Outreach Support, Lincoln Center was able to hone the expertise of our staff and teaching artists, as well as reach members of the community that would not otherwise have found this program."

"Connect2culture has referred a diverse community of participants from all parts of NYC to **Brooklyn Botanic Garden** Seasonal Highlights Memory Tour.

Connect2culture has provided extensive information about dementia that enabled us to design and implement a program that is enriching and restorative for people with memory loss and their caregivers. Connect2culture continues to provide invaluable support and training to raise awareness and support cultural institutions."



Photos:
Brooklyn
Botanic
Garden



Photos: Arts & Minds

"**Arts & Minds** has worked closely with the staff at CaringKind since our founding in 2010. They opened their Caregiver Training and Support Group Leader Training to me, a museum professional new to the world of dementia care. Since then, Arts & Minds has been a connect2culture partner, and many participants have found their way to our programs at The Studio Museum in Harlem, the New-York Historical Society, El Museo del Barrio and The Metropolitan Museum of Art through CaringKind."

– Carolyn Halpin-Healy, Co-Founder with James M. Noble, MD, Arts & Minds



Photo: The Rubin Museum

"**The Rubin Museum** is proud to be a connect2culture cultural partner. The ongoing training and support we've received from CaringKind has helped us develop and promote our Mindful Connections program. We would also like to recognize and thank our participants and their caregivers, we are deeply grateful for your dedication to our program. You have made our museum a more enriching space and we look forward to seeing you each month."

Mindful Connections is supported in part by the Milton & Sally Avery Arts Foundation.

"As a longtime connect2culture partner, **the American Folk Art Museum** has seen real and sustained benefits from working with CaringKind. Our Folk Art Reflections program has grown significantly because of the exposure and support given through partnership with connect2culture. New families looking for critical resources are able to connect with the Museum and take advantage of its offerings because of the outreach and education CaringKind provides to the community. Connect2culture acts as a dedicated advocate for all stakeholders – it provides necessary professional development opportunities for my staff, and a bridge between families navigating change and cultural institutions striving to provide quality programming to communities affected by Alzheimer's disease."



Photos: The American Folk Art Museum



Photos: Orpheus Chamber Orchestra



"**Orpheus Chamber Orchestra** was honored to partner with CaringKind on the pilot of "With Music in Mind;" two performances in May at the Hebrew Home in Riverdale and Brooklyn Museum. We are grateful to connect2culture for this opportunity to bring our music to people in New York City who would otherwise be unable to visit the concert hall. Orpheus will continue performing for people living with Alzheimer's disease and dementia and their caregivers through our "Orpheus Reflections" program beginning in fall 2018."

In the Absence of a Cure, Good Care is What We Need



CAROL BERNE

Senior Vice President of Development
cberne@caringkindnyc.org

Earlier this month news broke that Lilly and AstraZeneca, two very large drug companies, abandoned Alzheimer's drug trials for their late-stage Alzheimer's treatment. This comes following the announcement in January that Pfizer plans to end its research efforts to discover new drugs for Alzheimer's and Parkinson's diseases. How very disappointing for all of us who have been patiently waiting, and hoping for some positive development on the Alzheimer's front.

This news also calls to mind that in the absence of a prevention, treatment, or cure, the work of CaringKind could

not be more relevant or important for today. Every day you hear or read about caregiving and the emotional, physical and economic toll it takes on a family. This is difficult work that only those who are caregivers truly understand.

For more than thirty years, CaringKind has been at the forefront of dementia care and over the years we have developed many programs to make the lives of caregivers a little better and easier. One such program is connect2culture, which is the focus of this issue of the newsletter. Living and working in New York City, the cultural capital of the world, it is hard to imagine that there are so few cultural resources that are open and welcoming to people with dementia and their caregivers. Connect2culture is opening the door to the richness of the arts for this community, be it a live music performance at Lincoln Center, or attending a concert of Orpheus Chamber Orchestra, exploring nature at a botanical garden or visiting a

museum. Connect2culture ensures that staff at these institutions, from the security guard to the musician to the educator, are knowledgeable about Alzheimer's disease, the best way to present information, and how to make the overall experience a rewarding and enriching one. Dementia caregiving is isolating and lonely, and yet community can be found in music, art and nature.

As with all our programs at CaringKind, we rely upon donor support to make our work possible. Our connect2culture program has received support from the Andrew W. Mellon Foundation, Inc., the Burpee Foundation, Inc. and Art for Alzheimer's, as well as from individual donors.

If you wish to learn more about this program and how you can support connect2culture or our other services, please contact me at 646-744-2905 or cberne@caringkindnyc.org.

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

Planning Today for Tomorrow

When CaringKind wants to launch a new program or expand in new directions, we are 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 contact Carol Berne at 646-744-2905 or via email at cberne@caringkindnyc.org.

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



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



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

Ways to Give

Giving by Check

Please make checks payable to CaringKind and mail to:
360 Lexington Avenue, 3rd Floor
New York, NY 10017

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, 3rd 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.**

Forget-Me-Not Gala 2018



(left to right) CaringKind Board member and auctioneer, Jonathan S. Henes; CaringKind Board Chair and event chair, David Z. Hirsh; 2018 TackleALZ NYC team Coach, Ned Marks, CaringKind Founding Director, Lou-Ellen Barkan; Corporate Leadership Honoree, Hussein K. Manji, MD, Janssen R&D; CBS 2 Medical Reporter, Dr. Max Gomez; Master of Ceremonies and Emmy and Tony Award Winner, David Hyde Pierce, and CaringKind President & CEO, Jed A. Levine.



Dr. Max Gomez, CBS 2 Medical Reporter; CaringKind Founding Director, Lou-Ellen Barkan, honoree of the Special Appreciation Award; Tony Award winning actor, Alzheimer's advocate and event emcee David Hyde Pierce.



John Fiore and Board members Marianne Dziuba-Fiore and Jeffrey N. Jones.



CaringKind President & CEO Jed A. Levine and CaringKind Founding Director Lou-Ellen Barkan.



David Hyde Pierce makes opening remarks.



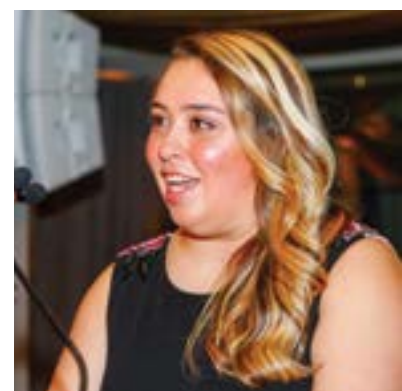
Dr. Max Gomez presents Hussein K. Manji, MD, Janssen R&D, with the Corporate Leadership Award.



CaringKind Board member, Elvira Bisignano and Bruce Wild.



Ned Marks, Blondetourage Coach, accepts the Young Leadership award on behalf of the entire 2018 TackleALZ team.



Simone Rodriguez, BruCrew Team Captain, accepts the Young Leadership award on behalf of the entire 2018 TackleALZ team.



Members of the 2018 TackleALZ NYC team which was honored with the Young Leadership Award.



TackleALZ team members Megan Williams, Michelle Pelan, and Simone Rodriguez.



Liz and David Hirsh and family.



Husseini K. Manji, MD, Janssen R&D, accepting the Corporate Leadership Award.



CaringKind Board Members and Members Emeritus: **Back row:** Stephen P. Casper, Sharon K. Kilmer, Jonathan S. Henes; John R. Latham, Elaine Thomas, Jeffrey N. Jones; Judith H. Itkin, David Hirsh, Wayne S. Miller. **Middle row:** Nathan Halegua, Elvira Bisignano, Marilyn L. Cohen, Heath B. McLendon, Lori Oscher Friedman, Pauline Yeung-Ha, Susan V. Kayser, Esq., Maria B. Diaz. **Front row:** Marianne Dziuba-Fiore.



CaringKind Board member, Jonathan S. Henes kicks off the live auction.



CaringKind Board member, Wayne Miller and Lisa Miller.



CaringKind Board members, Elaine Thomas and Lori Friedman and CaringKind Founding Director, Lou-Ellen Barkan.



CaringKind Board member, Jim Lavelle and Michelle Lavelle.



Lou-Ellen Barkan and Jillian Foster.



Dr. Richard Isaacson; Dr. Warachal Faison; Dr. Peter Davies; Dr. Mary Sano; CaringKind Founding Director, Lou-Ellen Barkan; Dr. Mony de Leon; Dr. Silvia Fossati Dr. Jose Luchsinger; Jed A. Levine, President & CEO at CaringKind.

Connect to Culture: An Artist's Perspective on Caregiving

by James Campbell

James Campbell is a freelance writer based in New York City. He also works with a humanitarian organization that advocates for child rights at the United Nations.

CaringKind's Loraine Halis Lecture on the Art and Science of Caregiving, has always provided an outlet to examine the social, political, moral, and ethical facets of caregiving. On April 23, at TheTimesCenter in New York, Caringkind added aesthetics to this tapestry of lecture topics with Connect to Culture: An Artist's Perspective on Caregiving.

Dorene Scolnic, daughter of Loraine Halis, opened the evening by sharing a story about art's power to help deal with a disease that affects both memory and identity. A painting of her mother as a young woman became a focal point of her room after she had been diagnosed with Alzheimer's. It stimulated her mother to talk about her life and acted as a reminder "not just of who she had been, but who she still was."

CaringKind's Founding Director Lou-Ellen Barkan carried Ms. Scolnic's deeply personal sentiment by reflecting on how she "became her own client" when

she became her mother's caregiver and discussed the need to accept the world on her mother's terms.

Before introducing the panel, CaringKind's President and CEO Jed A. Levine contemplated the words of theologian Thomas Merton, who said, "Art enables us to find ourselves, and lose ourselves at the same time." This sentiment lingered over the evening's conversation, as the panel discussed the ways in which art helps caregivers to manage the loss of self embedded in their role, and the desire to escape their present reality.

The panel encompassed caregivers who make art, and those who ensure that art is accessible and relevant to caregivers. Mark Dziejwulski is an artist and architect whose work is inspired by his experience as a caregiver for his mother. He looks at the ways in which communication is not simply verbal, but also requires presence. Laura Sloan manages the Rubin Museum's Mindful Connections program for visitors with memory loss and their partners. Meredith Wong manages connect2culture, a cultural initiative at CaringKind, which trains educators at cultural institutions to create and implement programs for people with Alzheimer's and dementia.

Throughout the evening, the three panelists landed on the concepts of inclusion and the self. Ms. Sloan described how the Rubin Museum covers issues pertinent to people with dementia and caregivers: health and wellness, protection, and mindfulness to name a few. The space of the museum itself, warm and inviting with a quiet ambiance, lends itself to creating peace and serenity caretakers so desperately need.

Ms. Wong explained how connect2culture's programs create an individualized and inclusive experience by encouraging museum staff to add different sensory layers to the exhibits, so "someone who is not able to verbalize can respond to a different sensory experience."

This idea of layers of experience dovetails with Mr. Dziejwulski's sculpture *Layers of Self*, which consists of individual panels of painted glass bolted together to create a three dimensional bust. Mr. Dziejwulski spoke of the role of art in creating a shared, inclusive experience for both him and his mother, where he was indulging his passion for art and, "She was living in the moment. She couldn't worry about the past, she couldn't be afraid of the future so the moment was what she had."



The 2018 Loraine Halis Lecture Panel on stage at TheTimesCenter.



CaringKind's President & CEO, Jed A. Levine, moderator; Mark Dziejwulski, a full-time caregiver and an accomplished artist and architect; Laura Sloan, the Manager of Docent and Access Programs at the Rubin Museum of Art; Meredith Wong, CaringKind's Manager of connect2culture

Play to Remember: An Overnight Softball Game

In an effort to raise critical funds and awareness about the round-the-clock demands on Alzheimer's and dementia caregivers, Hebrew Home at Riverdale and CaringKind cosponsored an overnight, one-pitch, double-elimination co-ed softball tournament fundraiser held from 10:30 p.m. on June 22 until 6:00 a.m. on June 23. The timing was symbolic – the most difficult hours for those living with Alzheimer's disease or dementia and their caregivers take place during these hours.

The tournament took place in Scenic Hudson Park in Irvington, NY. Approximately 100 players from eight different teams across Westchester competed that evening, and wore uniform patches participating to honor someone affected by Alzheimer's or dementia.

Joining the nearly 100 spectators was Brian Smith, Mayor of Irvington, who threw the first pitch. Other highlights of the event included a silent auction, raffles, assortment of food trucks, breakfast and a trophy presentation for players, celebrating the winning team, The Yellow Jackets. Thanks to the amazing effort of those involved, the event raised nearly \$8,000 which was split between Hebrew Home at Riverdale and CaringKind.



CaringKind President & CEO, Jed A. Levine; Mayor of Irvington, NY, Brian C. Smith, Hebrew Home at Riverdale's COO, David V. Pomeranz



CaringKind President & CEO, Jed A. Levine poses with Team Hebrew Home at Riverdale.



Team Hebrew Home at Riverdale in action.

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The Heart of Alzheimer's Caregiving

Invites you to the 31ST Annual Research Meeting
**Eat, Sleep, and Be Merry:
 What We Know About Brain Health**



Date: Monday, October 22, 2018

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

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

RSVP: 646-744-2900 or
www.caringkindnyc.org/AnnualMeeting

Beware of Phone Fraud



LOU-ELLEN BARKAN
Founding Director
lbarkan@caringkindnyc.org

These days when the phone rings, it may be a machine on the other end. Or, if not a machine, a perfect stranger, but one with a friendly voice. This person may ask you to confirm personal information, to register for a product or service or to buy something new. They may even reference your personal credit cards, bank account or address.

If you are anything like me, your first instinct is to respond politely and, if you

are uncertain about what they are asking, to ask for more information. *Don't do it!* Anything you say may be recorded.

While there are many versions of this scam, there is one particularly dangerous version which goes something like this.

A friendly voice asks, "Hello. Am I speaking to Joan Smith?"

And you respond, "Yes. This is Joan Smith."

Your response has been recorded. Later, you may see a false charge on your credit card statement. When you challenge the charge, the credit card company will play back your "Yes" to confirm that the charge was legitimate.

We know that these calls are perpetrated by criminals. Their goal is to take advantage of you and your good name. The only way to stop them is to resist your instinct to be polite. *Hang up immediately without responding!* If you don't recognize the name or organization that is calling, and if this is a cellphone call, block the number.

If your experience is anything like mine, the less often you respond to these calls, the fewer calls you will get. So, be smart and be cautious when picking up the phone. In my opinion, we all play a role in protecting ourselves!

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Music resonates in very significant ways with people who have Alzheimer's and dementia – awakening within them memories and feelings long ago forgotten. This is precisely why CaringKind's connect2culture® program partnered with the Orpheus Chamber Orchestra for a very special concert performed specifically for an audience made up entirely of individuals with Alzheimer's and dementia and their caregivers.



NY 1 News and News 12 Brooklyn were both on site at the Brooklyn Museum this May to capture footage and report on the event. NY 1's coverage included an interview with CaringKind's new President and CEO Jed Levine.

And just like the arts, technology is having an increasingly important role in the Alzheimer's community. In April, CaringKind hosted its 2nd annual Technology Fair, featuring more than twenty vendors who showcased a broad array of products that assist people with Alzheimer's and dementia, as well as their caregivers. Hundreds of caregivers came out to our Lexington Avenue office and got hands-on experience with technologies that can make their lives easier. Dr. Max Gomez, CBS 2 Medical Reporter, was given an exclusive to cover the event. There he interviewed Jed about how helpful these technologies can be for individuals and families. Dr. Gomez even tried out the virtual reality

platform, which is designed for the 65+ population, allowing residents of senior living communities to explore the world. The Channel 2 coverage was picked up by MSN, which gets millions of viewers.

Broadway World and New York City Patch both reported that Tony Award winning actor, tireless Alzheimer's advocate and longtime supporter of CaringKind, David Hyde Pierce would serve as emcee for this year's "Forget-Me-Not" Gala.

Thanks to the efforts of CaringKind's Wanderer's Safety Program, WPIX-TV, Channel 11 and the Washington Heights Patch both reported on New Yorkers who wandered and went missing, seeking New York City residents to keep an eye out for their missing neighbors. Both of the women who went missing were found and returned home safely.

The Upper West Side Patch reported on the TackleALZ NYC game that took place in May. The piece included several photos of the Blondetourage and the BruCrew teams decked out in their CaringKind orange and blue.

Lou-Ellen Barkan's April "Care Chronicle" column provided advice on living alone with Alzheimer's or dementia. Her take? It really depends on how far advanced the disease is. She provided tips, however, for families whose relatives are living

alone such as leaving a set of keys with a trusted neighbor, asking a friend or relative to look in on them when you can't be there, and not letting mail pile up. She also advised caregivers keep an eye on food expiration dates, that medication is being taken, and to ensure that electrical appliances are in good working condition.

In May's edition of CNG's "Care Chronicle," Lou-Ellen gave a nod to a special hero in her life – her mother who had dementia and for whom she served as caregiver. Lou-Ellen praised her late mother's caregiving efforts for her father and thanked her for instilling in Lou-Ellen enough strength to be a caregiver herself. And, interestingly, she touted her mom's understanding of just how important technology was to caregiving.

This spring, the podcast Grey Area did a segment that focused on art and dementia. The reporter mentioned CaringKind as a resource, which we hope helped spread the word to New Yorkers facing an Alzheimer's or dementia diagnosis.

And, once again, the media has been great to CaringKind by including our events such as our free educational meetings in their print and online calendars.

We'll see you in the news!

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2018 Athletic Events Summary



JESSICA GONZALEZ
Director of Constituent Events
jgonzalez@caringkindnyc.org

Spearheading our 2018 events, on Sunday, March 18, were the dedicated athletes who ran in the United Airlines Half-Marathon and braved temperatures below freezing. Training was hard due to a long winter, but over 30 athletes, including Team Otsuka of Otsuka Pharmaceuticals, donned their CaringKind shirts and raced the 13.1 miles on a new course ending in Central Park. The course began in Brooklyn, at Grand Army Plaza, and sent runners across the Brooklyn Bridge, through lower Manhattan and then north on the FDR Drive until 42nd Street. These Athletes to End Alzheimer's raised \$64,000. Thank you!

Next was the TD Five Boro Bike Tour. In the early morning of May 6th, CaringKind's team gathered to warm up and motivate each other before the race. Our team consisted of new bikers like Nais, Benny, Wiley and Karina and some familiar faces. Riders like Gordon Linton, Alex Cuesta and Carlos Cueto have been riding with us since 2013 to show their support for CaringKind's work. Gordon even persuaded a reporter from News12 to interview him, so he could explain why CaringKind and Alzheimer's are so important to him! The rain held off and our riders set off from lower Manhattan to begin their 40-mile journey. The CaringKind bike jersey was a great conversation starter and this allowed our riders to share their stories with fellow



riders. These Athletes to End Alzheimer's raised \$23,000.

Only one week later, TackleAlz NYC took to a new field having already raised a record amount to support CaringKind's programs and services. Columbia University's Lawrence Wien Stadium served as the battleground for the 8th annual TackleAlz game. Both teams worked together to make 2018 a truly successful year in fundraising, heading into the game with a total of over \$200k! And, for the third consecutive year, Blondetourage was able to surpass their goal of #100KbyGameDay. Also, this year the players were able to have the initials of the person they were playing for printed on their sleeves to keep that person close to them as they played to Tackle Alzheimer's.

The biggest challenge to game day was the weather. Lightning was predicted for late afternoon, so to stay safe our players and coaches agreed to move the start time four hours ahead.

The BruCrew received the first touchdown about 5 minutes into the game, setting the stage for tough competition. The Blondetourage fired back and was able to tie the game 13-13 by the end of the first quarter. NFL veterans Bobby Sewall and Dan Upperco

were on hand to show their support for CaringKind and TackleAlz. The BruCrew worked creatively from the sidelines using pictures and logos to call their plays, and they were able to pull away from the Blondetourage with a score of 25-13 heading into the 4th quarter. It was a tense 4th quarter with both teams making additional gains, but ultimately the BruCrew were crowned the 2018 TackleAlz NYC champions, with a final score of 38-25. The day ended with the BruCrew holding the game trophy and the Blondetourage with the fundraising trophy.

In July we cheered on our Tri-Athletes who ran, biked, and swam in New York City to support CaringKind's programs and services. We thank them for their support.

Our NYC Marathon runners are off to a strong start! Weekly training began July 9th. Several of our runners have been caregivers for parents, grandparents and other relatives. They train and race in honor of those loved ones. There are still a few spots on the team so if you'd like to run with us, please email us at: athletes@caringkindnyc.org.

Our athletes continue to shine a light on the impact of Alzheimer's demonstrating that all ages are affected by this disease.



2018 TackleALZ



Five Boro Bike Tour

(from left) Benny Kaufman, Carlos Cueto, Wiley Kidd, Jessica Gonzalez, Nais Shukla, Gordon Linton, Alex Cuesta



Half Marathon

(from left) Steve Lesh, Beth Ferriola, Anneka Bjorkeson, Noah Berch, Ali Cohen



Half Marathon

Ratan Ratnesh
(Team Otsuka)

connect2culture

Partner Programs

American Folk Art Museum Folk Art Reflections

Contact:
Rachel Rosen, rosen@folkartmuseum.org,
212-595-9533 ext. 381

Arts & Minds at:

El Museo del Barrio (en español)

The New-York Historical Society

The Studio Museum of Harlem

Contact/Favor de contactar:
Nellie Escalante, nellescalante9@gmail.com,
646-755-3726

Brooklyn Botanic Garden Seasonal Highlights Memory Tour

Contact:
Joanne D'Auria, jdauria@bbg.org, 718-623-7267

Brooklyn Museum Brooklyn Afternoons

Contact:
Lindsay Reuter, access@Brooklynmuseum.org,
718-501-6520

Brooklyn Public Library

Contact:
Judith Vigo, jvigo@bklynlibrary.org,
718-230-1760 ext. 51141

Intrepid Sea, Air & Space Museum The Stories Within

Contact:
Brigid Tuschen, access@intrepidmuseum.org,
646-381-5158

Jewish Museum JM Journeys

Contact:
Samantha Schott, sSchott@thejm.org,
212-423-3289

Lincoln Center Lincoln Center Moments

Contact:
Accessibility and Guest Services,
access@lincolncenter.org, 212-875-5375

Memory Arts Café

Contact:
Gary Glazner, 718-499-7701

The Met Cloisters Sights and Scents

Contact:
Leslie Bussis Tait,
Leslie.Tait@metmuseum.org,
212-650-2280

The Met Fifth Avenue MetEscapes

Contact:
Rebecca McGinnis, Marie Clapot,
Jan Ingvalson, Cristina Vanech
access@metmuseum.org, 212-650-2010

Museum of Modern Art Meet Me at MoMA

Contact:
Lara Schweller Lara_Schweller@moma.org or
accessprograms@moma.org, 212-408-6347

Queens Museum Creative Imagination

Contact:
Mitra Dejameh, mitra@queensmuseum.org,
718-592-9700 ext. 136

Rhythm Break Cares Tea Dance Social and Dance for Dementia

Contact: Stine Moen, rbcare@gmail.com,
646-742-9014

The Rubin Museum of Art Mindful Connections

Contact:
Laura Sloan, access@rubinmuseum.org,
212-620-5000 ext. 319

The Unforgettables Chorus

Contact:
unforgettables.chorus@gmail.com



Photo: Arts & Minds



Photo: Kevin Yatarola,
Lincoln Center Moments



Photo: NY Botanic Garden



Photo: American Folk
Art Museum

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Caregiver Storyteller

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While all caregiving stories convey a sense of loss, there is also a surprising amount of fortitude, loyalty, gratitude, joy, and humor. These are their stories.

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<http://www.caringkindnyc.org/podcast/>

New episodes available bi-weekly.

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:

August 10	12:00 - 2:00 p.m.	Manhattan
August 15	5:30 - 7:30 p.m.	Manhattan
August 21	5:00 - 7:00 p.m.	Brooklyn
September 14	12:00 - 2:00 p.m.	Manhattan
September 25	2:00 - 4:00 p.m.	Brooklyn
September 26	5:30 - 7:30 p.m.	Manhattan
October 5	12:00 - 2:00 p.m.	Manhattan
October 16	5:00 - 7:00 p.m.	Brooklyn
October 17	5:30 - 7:30 p.m.	Manhattan

Upcoming Date in Spanish:

September 20	1:00 p.m. - 3:00 p.m.	Manhattan
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Contact our 24-hour Helpline at 646-744-2900 for more information.

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	
August 6	12:00 - 1:30 p.m.
August 20	5:30 - 7:00 p.m.
September 10	12:00 - 1:30 p.m.
September 17	5:30 - 7:00 p.m.
October 1	12:00 - 1:30 p.m.
October 15	5:30 - 7:00 p.m.

*Upcoming Date in Chinese
(Mandarin & Cantonese):*
Manhattan

September Call 646-744-2900
for Date & Time

Seminars for Professionals

Understanding Dementia for Professionals:

September 12	3:00 - 5:00 p.m.	Manhattan
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Enhancing Communication with Persons with Dementia:

October 10	3:00 - 5:00 p.m.	Manhattan
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The Seminars are free of charge.

Two (2) Social Work Continuing Education units are available for a fee.

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:

September 6	5:30 - 7:00 p.m.	Manhattan
October 4	5:30 - 7:00 p.m.	Manhattan

Placing Your Relative in a Nursing Home

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

Upcoming Date in English:

Manhattan	
September 18	5:30 - 7:00 p.m.

Monthly Education Meetings

Meeting topics change monthly.

All meetings from 6:00 – 8:00 p.m.

Monday, August 13

Design for Dementia: Safety In Your Home

- Learn how design can increase function, safety, mobility, and well-being.
- Explore hallmarks of dementia-friendly designs and how they can make caregiving easier.
- Understand the connection between home safety, furnishings, flooring, and memory cueing.

Speaker:

Rosemary Bakker, MS, Certified Interior Designer, Dementia Specialist and Gerontologist, Published Author, AARP blogger, and President of Age-Friendly Design, Inc.

Monday, September 10

Staying Alert: Early Signs of Dementia and How to Keep Your Brain Healthy

- Learn to differentiate signs of normal aging versus early signs of dementia.
- Discover how to maximize your brain health.
- Review resources that can support your cognitive concerns.

Speaker:

Anne C. Sansevero, RN, MA, GNP, CCM Aging Life Care® Professional, Founder & CEO, HealthSense LLC

Monday, October 1

Lewy Body Dementia: One of the Most Common Diseases You've Never Heard Of

- How is LBD different from Alzheimer's disease and Parkinson's disease?
- Why is it often misdiagnosed?
- What kind of support is available for caregivers in NYC?

Speakers:

Norma Loeb, Founder & Executive Director, Lewy Body Dementia Resource Center of New York

Dr. Judith C. Ahronheim, MD, MSJ, Internist and Geriatrician

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 Dates in English – In Manhattan:

September 10, 17, 24, Oct. 1 Evenings

Upcoming Dates in Spanish – In Manhattan:

August 7, 14, 21, 28 Evenings

September 27, Oct. 4, 11, 18 Afternoons

**To register, please call our
24-hour Helpline at
646-744-2900
or visit www.caringkindnyc.org.**

**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 for providing meeting space:**

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Carter Burden/Leonard Covello
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Heights & Hills
Selfhelp Alzheimer's Resource Program
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caringkind chronicles

Writer: Jennifer Camper Artist: Ivan Velez

Episode 7 Previous episodes: caringkindnyc.org/comic



Connect2culture® supports museums and other cultural organizations to develop ongoing programs for people living with dementia and their caregivers. For information, call 646-744-2900 or go to www.caringkindnyc.org/connect2culture.

caringkindnyc.org



caringkind Alzheimer's

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MANHATTAN
Sunday
Oct. 14, 9am
Riverside Park

QUEENS
Sunday
Sept. 16, 9am
Flushing Meadows
Corona Park

BROOKLYN
Sunday
Sept. 23, 9am
Coney Island
Boardwalk

STATEN ISLAND
Sunday
Sept. 30, 9am
South Beach



SIGN UP TODAY!

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24-hour Helpline 646-744-2900

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**Doggie Dugout
Costume Parade!**
(Manhattan Walk)

CaringKind was formerly known as the Alzheimer's Association, New York City Chapter.