

alzheimer's association®

New York City Chapter



ALZHEIMER'S
DISEASE
IS THE 6TH LEADING
CAUSE OF DEATH
IN THE UNITED STATES



IT KILLS
MORE THAN
BREAST &
PROSTATE CANCER
COMBINED



EVERY
67
SECONDS

SOMEONE IN THE
UNITED STATES
DEVELOPS THE DISEASE

MORE THAN
5 MILLION
AMERICANS
—are living with—
ALZHEIMER'S



BY 2050, THIS NUMBER
COULD BE AS HIGH AS

16
MILLION



ALZHEIMER'S
DISEASE CANNOT BE



PREVENTED



CURED



SLOWED

FROM 2006-2010,
THE NUMBER OF
DEATHS
FROM OTHER MAJOR DISEASES



68%

WHILE DEATHS FROM
ALZHEIMER'S
INCREASED



MORE THAN 60% OF ALZHEIMER'S & DEMENTIA CAREGIVERS ARE WOMEN

— ALMOST —



TWO-THIRDS
of
AMERICANS
with
ALZHEIMER'S
DISEASE
ARE

Women

WOMEN
IN

THEIR 60s

... ARE ABOUT ...
2 TIMES MORE LIKELY
TO DEVELOP ALZHEIMER'S
over the rest of their lives
... THAN ...

BREAST CANCER

Alzheimer's Association 2014 Alzheimer's Disease Facts and Figures

INSIDE

Summer 2014

► Don't miss the chance to dedicate a Bryant Park Chair p. 28

in 2014.

ALZHEIMER'S & OTHER
DEMENTIAS
WILL COST THE NATION \$214 BILLION

BY 2050, THESE COSTS
COULD RISE
... AS HIGH AS ...



\$1.2
TRILLION

New York City Chapter

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Dear Friends,

Behind every Alzheimer's statistic is a life — a family — a community — forever changed by this devastating disease. So let's take a look at some of the faces behind the facts and figures.

Fact: Every 67 seconds an American develops Alzheimer's disease. A startling fact for sure, but not all the faces behind this number are what you'd expect. One in ten Americans with Alzheimer's is under the age of 60. These are people who until recently were enjoying successful professional and personal lives. They were driving their kids to soccer practice, owning restaurants, volunteering at the local food bank, balancing their checkbooks. And every 67 seconds, one of their lives dramatically changes with the development of Alzheimer's disease

Fact: More than 60% of dementia caregivers are women. My parents retired to Florida in 1984. But when my father's dementia was diagnosed, it quickly became clear that their retirement plan had not anticipated a long-term chronic illness. Within a few years, he required 24-hour care. To preserve their limited financial resources, Mom initially struggled to care for him alone and, like so many women of her generation, she suffered physically, emotionally and financially.

Fact: Almost 66% of Americans with Alzheimer's are women. Nine years after my father died, I admitted my 88-year-old mother to assisted living. She was recovering from chemotherapy and already exhibiting signs of dementia. When I visited her after two months of community living, I was told that Mom, who had never held a paying job, had re-invented herself as an attorney with a second career as a big band vocalist. Like other children of Alzheimer's, I was at first shocked and then overjoyed by her new story. The independent, energetic

and creative woman I called "Mom" hadn't changed a bit!

Fact: Alzheimer's is the sixth leading cause of death in the U.S. but experts say it could be as high as number three! There are a number of factors behind the discrepancy of this disturbing statistic. However, one contributing factor remains the shame associated with dementia. Every day, I meet families who are embarrassed by an Alzheimer's diagnosis. Let's be clear: Alzheimer's is a fatal, untreatable physical illness, no different than cancer or ALS. But, even after a death, many families are ashamed to admit their relative had Alzheimer's.

Fact: Research dollars for breast and prostate cancer dwarf the funds allocated for Alzheimer's, but the number of people with Alzheimer's far exceeds these two diseases combined. In my mind's eye, I see hundreds of bright, eager scientists who are interested in neurological illness and are committed to developing effective therapies for Alzheimer's. But without adequate funding, this army of brilliant minds will walk away from their groundbreaking work to focus on better-funded areas of research — a tragedy in the making.

Fact: Within 30 years as many as 16 million Americans will have Alzheimer's. To see the face of someone affected by Alzheimer's, all we have to do is look in the mirror. Statistically, if we live long enough, many of us will develop the disease and all of us will be affected in some way — either personally, in our role as caregiver, or by the enormous strain it will put on the American healthcare system.



Lou-Ellen Barkan
President & CEO
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So, why do facts and figures matter? Numbers compel politicians to action. Numbers drive research dollars and resources for care. The larger our community, the more visible we become and the stronger our voice, the harder it will be for elected officials, policy makers, corporate America and the voters to ignore us.

Statistically, if we live long enough, many of us will develop the disease and all of us will be affected in some way — either personally, in our role as caregiver, or by the enormous strain it will put on the American healthcare system.

I invite you to add your voice by joining us for the Walk to End Alzheimer's. Let's walk together to heighten awareness and create the resources that will lead to a new set of facts and figures and a brighter future for all of us.

Dear Readers,

For the first time in recorded history, there is an unprecedented number of persons living past 65, many well into their nineties and beyond. Unfortunately, with this record growth, the number of persons at risk for developing Alzheimer's and other dementias is also growing. But just talking about numbers is too easy.

It's better to ask what one person, one family with Alzheimer's is experiencing. We must try to remember that these numbers represent real people, real families – like yours and mine – whose lives are inexorably altered by an Alzheimer's diagnosis.

At the Chapter, we hear how this disease affects lives in ways large and small. A sampling reveals the vast complexity of issues and the intimate nature of how this disease profoundly touches individuals, their families and friends who are caring for them:

- A daughter recognizes that her mother can't write the monthly checks, and is paying some bills twice; others not at all. She is calling to find out where to get her mother diagnosed.
- There is a bed bug infestation in the apartment of a 93-year-old Brooklyn resident living with Alzheimer's.
- A recently diagnosed 58-year-old woman in the Bronx is looking for activities and engagement. She asks that we not put her on the mailing list as she does not want to receive mail from the Alzheimer's Association. She has not told her family members and neighbors that she has the disease.
- A friend is concerned about someone in his 80s living alone in Queens. He has a history of alcoholism and is estranged from his family, and now needs more care. Who will provide it?
- A niece who lives with her elderly aunt is concerned about

her progression into the advanced stages of dementia. She is worried that a cousin will place the aunt in a nursing home, leaving the niece no place to live, and no funds to rent another place.

- A son on Staten Island is concerned about his father's increasingly poor hygiene. He refuses to bathe or wash his hair, claiming he just did it yesterday.
- A daughter is terrified that her mother is going to die because of the stress of caring for her father. Her mother hasn't had a mammogram in years even though she is a breast cancer survivor.
- A wife in Harlem calls to report that her husband is missing again – for the third time this month – and she is frantic. He left between midnight and 4 a.m. She sensed that something was wrong and saw that he was gone.
- An "undocumented" woman with a history of stroke and multiple brain surgeries, now partially paralyzed and diagnosed with progressive dementia, is fearful of becoming homeless and living on the streets. She is not eligible for public assistance, and has no means to pay the rent.

These stories describe the emotional, social and financial cost of care and the anxiety and exhaustion of dementia caregivers. But callers can find help, comfort and support in the compassionate, informed responses of the Chapter's 24-hour Helpline and Care Consultation staff. Callers are referred to support groups



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and education meetings including Understanding Dementia, Legal & Financial Seminars and Placing Your Relative in a Nursing Home. They join Family Caregiver Workshops, take advantage of Early Stage Services and our MedicAlert® + Alzheimer's Association Safe Return® Program.

They receive information about community resources, day programs, home care, legal assistance, financial planning for long term care, and learn how to care for a person with dementia at every stage of the illness. And most importantly, they get the support of knowing they are not alone. They can openly discuss the issues, feel understood, and often feel relieved and "lighter" at the end of the call. We don't have a cure for Alzheimer's or a way of preventing or slowing down its symptoms, but we do know a lot about caring for the person with the disease and caring for the caregiver.

Behind the numbers are people, like you and me, struggling to come to terms with Alzheimer's disease. Call us. Often people wait longer than they need to. We regularly hear, "I'm so glad I made the call" or "I'm sorry I didn't know about you sooner." If you or someone you know needs our help, give us a call now at 24-hours a day, 800-272-3900. You won't be sorry you made the call.

It was a busy spring for the Chapter, and the media has been there each step of the way to capture important news and events in the Alzheimer's community.

This May, the Chapter held its fourth annual flag football competition, Blondes vs. Brunettes® (BvB), to raise funds and awareness about Alzheimer's and Chapter services. Lou-Ellen Barkan, Chapter President and CEO, and Team Blonde's Liz Johnson were interviewed in a live TV segment by Roger Clark of NY1 News. NY1 also featured interviews with several other players. The piece, which included footage of the teams practicing, aired several times throughout the week leading up to game day. You may have also heard Lou-Ellen on 1010WINS radio the day after the game talking about the importance of this event and how Alzheimer's disease affects women more than men.

Lou-Ellen and Candace Douglas, Director of Constituent Events at the Chapter, were interviewed in March on WABC-TV about the Alzheimer's Association 2014 *Alzheimer's Disease Facts and Figures* report. Dr. Sapna Parikh reported, asking Lou-Ellen and Candace about women and Alzheimer's, what it's like to care for someone with the disease, and the need for advocacy for both funding and research. Candace shared her personal experience with the disease and her grandmother's for whom she has served as a caregiver. Also taking interest in the report was 1010WINS, which interviewed Lou-Ellen about the latest statistics.

You may have also seen a Letter to the Editor in the *New York Daily News* by Lou-Ellen Barkan in response to the article reporting that chef, restaurateur and model B. Smith has been diagnosed with Alzheimer's in her early 60s. In the letter, Lou-Ellen said, "Black or white, rich or poor, famous or anonymous – no one is immune." She also stressed how the Chapter is here to help people with Alzheimer's or dementia, their families, and caregivers.

Getting the word out about Alzheimer's and dementia to the City's many diverse communities is a priority at the Chapter. Alejandro Berti, Dementia Care Trainer,

did a 30-minute interview on "En Comunidad," a Spanish-language public affairs TV program hosted by Council member Fernando Cabrera. The interview, which aired in April, covered Alzheimer's disease and more specifically, Alzheimer's and the Latino community.

Each year the Chapter holds its "Forget-Me-Not" Gala, An Evening to End Alzheimer's. A photo of Lou-Ellen Barkan and Dominic and Jane Chianese at the "Forget-Me-Not" Gala ran in Bill Cunningham's Evening Hours section in *The Sunday New York Times*. The event was featured on Broadway World's website announcing Dominic Chianese as the Chapter's Creative Leadership honoree. The piece also included a photo of Dominic. A reporter from *Newsday* interviewed New York Giant starting cornerback Prince Amukamara who was at the Gala with his wife Pilar. The *Newsday* piece included a wonderful quote from Prince about why he and his wife, whose father has early onset Alzheimer's, attended the event. Prince said, "Just to be educated more about it and maybe find some tips on how to handle it, maybe things that we don't know." This year's Gala also had a social media presence. Society media site Guest of a Guest posted a photo of Prince and Pilar Amukamara, Dominic Chianese and David Hyde Pierce from the event on Instagram. Additional coverage was included on their site. Paparazzi, including Getty Images and WireImage, also covered the event as did *Black Tie International Magazine*. Broadway World also ran an article and photo after the event.

Once again, print and online news calendars have included the Chapter's events in their coverage. Events such as the Gala, Interfaith Workshop, Theater Benefit with Broadway's "After Midnight," A New York State of Mind, Brooklyn Nets ENDALZ Awareness Game, call for marathon recruits, Annual Charles Evans Lecture on the Art and Science of Caregiving, and A Night of Cabaret were among the events featured.



Join Walking Wanda's Fight to End Alzheimer's

www.alznyc.org/walkingwanda

The Alzheimer's Association, NYC Chapter is proud to introduce Walking Wanda, our new Walk to End Alzheimer's mascot! Look out for her as she travels across the city, and the world, bringing our mission to end Alzheimer's to a neighborhood near you. Follow her travels by using #WalkingWanda on Twitter, Instagram and Facebook.

A Talk with New York City Department for the Aging Commissioner Donna Corrado



Jed A. Levine
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Chapter Executive Vice President, Director of Programs & Services, Jed Levine, interviewed Dr. Donna Corrado, Commissioner, New York City Department for the Aging, to get her perspective on Alzheimer's disease and aging in NYC.

Jed Levine (JL): Congratulations on your recent appointment, Commissioner! You are a terrific asset for NYC seniors. You and I have known each other for a long time. I think we first met in the early 90's at Catholic Charities.

Donna Corrado (DC): You were one of the first people I met at Catholic Charities. You were conducting a family caregiver training for caregiver groups with the case management program. It was an unbelievable series for staff and case managers. We immediately wanted it replicated.

JL: Yes, and we ended up continuing the training program at various locations.

DC: My recollection of this was that Catholic Charities had taken over one of the Brookdale Centers at Bay Ridge — the first social adult day center — we went on to open programs in Sheepshead Bay, Midwood, and Flushing. The challenge at the time was that there was no operating grant. We had to piggyback off the case management program. It was a funding challenge, but there was no doubt about the value of the program.

JL: Professionally, you have extensive experience with dementia. Do you have any personal experience with it?

DC: When I was growing up, my mom took care of her aunt and uncle, who both had dementia. My mom had four young children to look after, but on top of that, she cared for both

of them! I remember my mom would take us with her to their house — they lived four blocks away — throughout the day. We would go back and forth all day long. She would cook for them, bathe them, and care for them.

JL: So you personally experienced the sandwich generation?

DC: Yes, and in doing so, I could feel my mother's oppression — the burden of taking care of two older people and four children. But even then, when my mother eventually had to place her aunt in a nursing home, I remember her devastation.

More recently, my grandmother had Alzheimer's disease, and my sisters and I took care of her for a number of years — but we were all working; it was difficult. We had to place her in a nursing home, where she received excellent care for 13 years.

JL: That's a long time, and truly a testament to the care she got too.

DC: Yes, but it's never an easy decision to send your parent or grandparent to a nursing home. They're heart-wrenching decisions.

JL: Making that decision is tough. You often second guess yourself.

JL: Having that personal exposure and experience makes you even more sensitive and empathic to the challenges of families caring for an older relative, who cognitively, cannot participate in these decisions in the same way as cognitively intact elders.

DC: My sisters and I still talk about it. And, we make a point to talk about what we want when it comes to end of life issues so that we are all on the same page.

JL: We have always seen DFTA as our most important public partner, and we have a long historic relationship. Ours is the longest running partnership

between any Alzheimer's organization and a local Area Agency on Aging (AAA). We both have the distinction of being the largest organizations in our networks. New York was the first city in the country to offer an Alzheimer's unit. What are some of the services that DFTA offers for families dealing with Alzheimer's disease and dementia?

DC: We have a family caregiver program, caregiver support program, home delivered meals, social adult day centers, respite services, training and education programs, and counseling. In all there are nine caregiver programs.

We also need to look at how we are going to address the growing number of people with dementia — we need to reinvigorate that effort.

Services are available in English and Spanish.

JL: And to connect with DFTA, New Yorkers call 311?

DC: Yes, just call 311. At the Alzheimer's and Caregiver Resources Center within DFTA, we get calls from around the world from people with family members living in the five boroughs of NYC. They reach out for assistance — often referred through 311 — where an experienced social worker links callers with pertinent services, including the Chapter's MedicAlert®+Alzheimer's Association Safe Return®.

There is growing concern over the challenge of identifying long-term

services for people with younger onset dementia, as their age (younger than 60) works against referrals to AAA agencies, but there are alternative plans for emergency situations.

JL: With the increasing aging population, and the diversity of that community, there is a changing concept of what it means to be older. Being an older person is very different from what it was 40 years ago. What is your vision and DFTA's vision for meeting the needs of NYC's aging population?

DC: We are looking at serving diverse, immigrant populations that may/may not have access to benefits. How do we fulfill their basic needs — some don't have food and shelter — and meet their needs for security?

We also need to look at how we are going to address the growing number of people with dementia — we need to reinvigorate that effort. We are thinking of hosting conferences to discuss dementia in NYC.

From where I sit, I always find it helpful to have practical hands-on training and advice when faced with the issue of caring for a person with dementia. People want to know the day-to-day basics. The training I had from the Alzheimer's Association was invaluable—how to deal with difficult behaviors, sundowning, and how to take care of yourself and your environment to maintain safety.

JL: Once people know about these resources, they feel like they have discovered the Holy Grail. But there is an issue of people not knowing about these resources. What are your thoughts on how to improve this, and how can we work on this together?

DC: We need to embark on a campaign to change the face of aging in NYC. We are planning to create a marketing campaign around positive aging in NYC. We can work together to make New Yorkers aware of these services that DFTA and the Chapter have to offer.

JL: That's really exciting. There are so many families struggling on their own, and there is no shame in getting help.

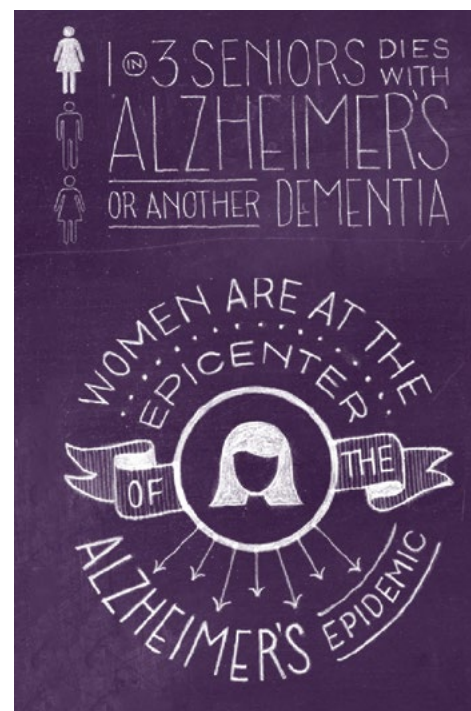
DC: And nobody can do it alone.

JL: Exactly. As you may have heard, we released a report with Comptroller Stringer's office in December, "Crisis for Caregivers: Alzheimer's Disease in New York City." With this report, we are working to make people aware of Alzheimer's disease as a public health issue. It is the third leading cause of death in the United States and the only one in the top 10 without an effective treatment or preventative measure. We plan to continue our work with the Comptroller's office as well as DFTA and DOHMH to develop a citywide plan for Alzheimer's disease.

DC: We have to come up with a comprehensive long-term plan. We have partnered with the Mayor, City Council, and the New York Academy of Medicine to create a comprehensive plan around making New York City an age-friendly city. While Age-friendly New York is a good start, there needs to be dementia friendly changes implemented too. (Editor's Note: Age-friendly NYC was created in the wake of demographic research indicating a population explosion of older adults in the next several decades. The initiative asks the city's public agencies, businesses, cultural, educational and religious institutions, community groups, and individuals to consider how changes to policy and practice can create a city more inclusive of older adults and more sensitive to their needs. For more information on the 59 initiatives making up Age-friendly NYC, go to www.nyam.org/agefriendlynyc/index.html).

JL: Anything else you would like our readers to know?

DC: At DFTA, we have a dedicated, committed staff — everyone is ready and willing to roll their sleeves up. We can work together and there is a lot of goodwill around Alzheimer's disease on many levels. And it is an important



issue that touches everyone. The political will is sure to follow.

JL: Thank you Donna, for sharing your thoughts and perspectives on aging, Alzheimer's and related issues. We look forward to continuing our partnership with DFTA in meeting the needs of all New Yorkers facing the challenges of Alzheimer's and related disorders.



Dr. Donna Corrado began her social work career at Catholic Charities, Diocese of Brooklyn in 1992, and in 22+ years with the agency provided leadership oversight to CCNS' 180 programs throughout Brooklyn and Queens, serving vulnerable populations from all walks of life, including persons with intellectual and developmental disabilities, youth, children, persons with mental illness, the homeless, persons with HIV/AIDS, and older adults. On February 18, 2014, she was appointed by Mayor Bill de Blasio as Commissioner for the NYC Department for the Aging.



Volunteer Recognition Event 2014

On March 25th, the Chapter hosted an evening to celebrate and thank our wonderful volunteers for yet another year of service. The evening started with a wine and cheese tasting that was followed by dinner. This year's honorees for their outstanding work in advancing awareness and advocacy were Craig Colfelt, DonnaMarie Arrigo and Sharon Corso.



Support Groups



Photo Credit: Susie Lang

Group Leader Recognition Breakfast

The Chapter's 115+ support groups are led by volunteers who are trained, supervised and supported by the support group program's staff members Wendy Panken, LCSW, and Sharon Shaw, LCSW.

Like all Chapter volunteers, group leaders make an enormously significant contribution to the Chapter's mission by providing the highest quality of services to caregivers and people with dementia.

To give you an idea of what group leaders do, they participate in a 32-hour training conducted by Sharon Shaw, LCSW; they lead biweekly groups, which are an hour and a half long; interview new members for their groups; attend monthly supervision groups and also educational workshops on topics relevant to their work.

On June 20th, we had a celebration to honor their commitment with a delicious breakfast provided and served by Dish Food & Events and a spectacular performance by Melinda Buckley, a Broadway performer, caregiver and group member, of portions her profoundly funny play called "Mother."

It's an understatement to say what a pleasure it is to be with and to work with the Chapter's group leaders.

To learn more about the support group program, please call Wendy Panken, LCSW, at 646-744-2917.

Caregivers and Mental Health Concerns



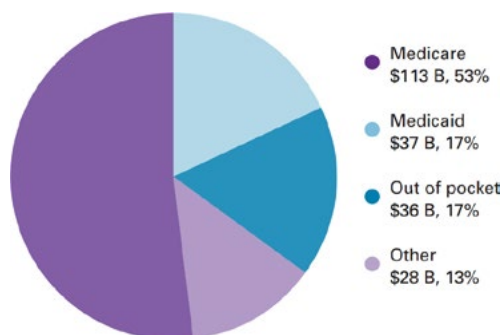
Anne Foerg
Manager, Care Consultation
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With the rising number of Americans who are and will be affected by Alzheimer's disease and related dementias, the unfortunate reality is that we can also expect an increase in the number of caregivers facing significant burden and stress as they work to manage the many challenges inherent in this role. It might be the son who is busy holding down a full-time job during the day just to have to rush home in the evening to relieve the aide who cares for his mother. Managing her nightly needs is another 12 hours of work, with his sleep as the casualty. Or it could be the wife who is struggling to manage all of the household activities — bill paying, grocery shopping, home repair — while also trying to care for the husband who will not leave her side. It may also be the daughter who loses her job only to be unable to find the time to look for a new one once she realizes her father can no longer be left alone.

What these caregivers share is a reality that does not allow for the time and space needed to care for their own needs — physical, emotional, financial, and social. Even the most solid coping skills are easily eroded with no respite from these daily challenges. It is for this reason that caregivers for people with dementia are at an increased risk of developing mental health disorders, such as anxiety and depression. Individuals with chronic mental health problems are particularly vulnerable. Not only must they learn to manage the new stress of caregiving responsibilities, but these caregivers are often caring for the person who functioned as their primary support, such as a parent or spouse. In effect, they are losing a primary source of support at the time during which it is most needed.

The consequences of allowing this crisis to go unaddressed are too serious to ignore. Studies show that caregivers for people with dementia abuse alcohol and other substances, including both prescription and non-prescription drugs, at a higher rate than non-caregivers. Not only do these behaviors represent an obvious risk to the health and safety of the caregiver, they also impair a caregiver's ability to meet the needs of the person with dementia. Sadly, untreated mental health and substance abuse problems also increase the risk that a caregiver will engage in abusive behavior, whether verbal, emotional or physical.

While the problem may seem clear, the solutions are not necessarily so. Counseling, support groups, and disease education are extremely



Total cost: \$214 Billion (B)
Aggregate Cost of Care by Payer for Americans Age 65 and Older with Alzheimer's Disease and Other Dementias, 2014

effective options for helping caregivers cope with the emotional toll of this role, but what if the caregiver does not have someone to stay with the person with dementia so he or she can attend a support group, an educational seminar, or an Alcoholics Anonymous meeting? What if the caregiver does not have insurance to cover the cost of individual counseling? These practical barriers are often the first of many that a caregiver encounters in the effort to obtain assistance. This is where the NYC Chapter's Care Consultation service can help. Our team of Care Consultants provides individualized



support to help caregivers craft a plan to access the available resources and get the needed care, while functioning as part of the support team that every caregiver needs to build. If you find yourself feeling overwhelmed, anxious, exhausted or depressed, please contact our 24-hour Helpline at 800-272-3900 and ask to speak with a Care Consultant.

Yet one does not have to wait for the crisis to occur to reach out for support. In fact, doing so as early as possible and allowing Care Consultants to assist in building a network of care can go a long way towards preventing caregiver burnout that often occurs as the person with dementia declines. Our Care Consultants provide one-to-one support — in person, over the telephone, or via e-mail — in order to help assess the needs of the caregiver and the person with dementia, create a plan of care, match them with local resources, and assist in navigating the complex system of long-term care. The needs of the caregiver are as important as the needs of the person with dementia, so we welcome caregivers to reach out to find the foundation of support they deserve.

Understanding the Emotional, Societal and Financial Strain of Alzheimer's

By Alex Turok

As U.S. healthcare costs rise faster than the price of other goods and services, we know that we must reduce costs, but without sacrificing the quality of care. As a nation, we remain hopeful that recent legislation improving access to care will help us achieve these goals. But in the Alzheimer's community, we know that unless the cost of caring for persons with Alzheimer's disease and other forms of dementia is addressed, we cannot achieve these goals.

The Alzheimer's Association 2014
Alzheimer's Disease Facts and Figures

While the direct costs of care may seem obvious and are easily measured, we should all be concerned about the underlying indirect costs of Alzheimer's

report provides the data to help us better understand the economic implications of our decisions.

There are several reasons why Alzheimer's disease in particular creates a tremendous economic burden for the taxpayer. First, the major risk factor for Alzheimer's is old age and as a result of the aging population of Baby Boomers, a record number of people are living longer. This trend suggests the potential for an exponential growth in Alzheimer's and related dementias — and an exponential increase in healthcare costs. In addition, not only does

Alzheimer's disease affect a large number of people, it affects them for a long time. The disease is chronic, lasting three to 20 years. Finally, the disease is progressive. As people with dementia progress through the stages of the disease from mild to severe, they lose the ability to care for themselves and require an increasing amount of costly care and support.

The specific costs of Alzheimer's can be direct or indirect. Direct costs of treatment include diagnostic testing, provider services (e.g. doctor visits, hospitalizations, etc.), prescription medications, over-the-counter products, and long-term care including both home and residential care. Alzheimer's and other forms of dementia are difficult to diagnose. As such, some physicians will perform a variety of tests which rule out conditions with similar symptoms as Alzheimer's. These could include laboratory blood tests, psychological evaluations, imaging exams, and in some cases genetic testing. These types of tests are costly, but a proper diagnosis is important in making treatment recommendations.

Provider services include physician consultations as well as hospitalizations, and people suffering from Alzheimer's use these services more frequently than those without the disease. While the existing prescription medications for the treatment of Alzheimer's are limited, many other medications are used to treat symptoms of the disease including depression and anxiety. For those people who remain in their homes there are many other products on the market to assist with home life such as safety equipment, GPS tracking technology for those who may wander, and disposable adult-diapers for those suffering from incontinence.

Perhaps the largest direct costs are related to personal and nursing care. As the disease progresses, people with the disease lose the ability to care for themselves; and when the provision

of care becomes too much for family members to handle alone, professional services are required. The Alzheimer's Association *Facts and Figures* report shows that these services can take the form of in-home care, adult day health centers, assisted living, and nursing homes. Persons with severe Alzheimer's require total assistance performing all basic functions including eating, bathing, and dressing themselves. Many deplete all of their savings to pay for, or in the process of planning to pay for, these exorbitantly expensive services. Since the vast majority of persons with Alzheimer's are over the age of 65, they are using public programs — Medicare and/or Medicaid — to pay for care. This is very expensive for all of us, since the Medicare costs of caring for an adult over 65 years of age is about three times more expensive for those with dementia than those without.

While the direct costs of care may seem obvious and are easily measured, we should all be concerned about the underlying indirect costs of Alzheimer's disease. An indirect cost may be tangible, such as the cost of training nurses in specialized Alzheimer's care. While this cost cannot be attributed to a single person it is indirectly incurred as a result of the disease. An indirect cost may also be intangible — a caregiver who must work fewer hours per week or leave the workforce entirely to care for a loved one represents a loss of productivity to the economy as well as an opportunity cost. The caregiver has lost wages that he or she may have earned if they did not have to care for a person suffering from Alzheimer's. According to the Alzheimer's Association *Facts and Figures* report, almost 18 billion hours of labor can be attributed to unpaid caregiving in 2013.

Many people with Alzheimer's suffer from additional conditions — such as heart disease, diabetes, kidney disease, or cancer — which

further complicates treatment and contributes to the economic impact. For a person with dementia, any other chronic or acute illness becomes more difficult to manage as the person requires consistent assistance to comply with their physician's recommendations. This potential lack of compliance, coupled with the higher costs typically associated with old age, contributes to higher medical bills from hospitals and doctors.

There is a lot that we can do to reduce the economic burden of Alzheimer's disease. Firstly, look for opportunities to donate and support organizations that assist people with Alzheimer's or other forms of dementia. Fund nonprofit programs such as the Alzheimer's Association to help advance research, provide support, and be the voice of our community in national debates.

Secondly, advocate for increased research and development for Alzheimer's. It is estimated that over three-fourths of the total costs are incurred when symptoms become severe, so therapies which delay symptoms, or slow the progression of Alzheimer's, would be one critical way to reduce costs. Congress currently invests more in cancer, cardiovascular, and HIV research. Encourage your elected officials to support funding for Alzheimer's research.

Furthermore, pharmaceutical companies are cautious about spending in this category. Most

research studies are unsuccessful and the regulatory process has become more complex and takes longer. We must encourage the Food and Drug Administration to give preferential treatment to those drug companies willing to make a bet on Alzheimer's. Any new medication should be given an expedited review process.

Lastly, share your newfound knowledge about the costs of Alzheimer's and increase awareness with your friends and family. This disease most often impacts our daughters, mothers, and grandmothers. Homemakers especially fall into the trap of "sandwich caregiving", which requires them to raise children while also spending time caring for a parent. Not unlike the breast cancer and HIV/AIDS movement, we must now create a rallying cry for Alzheimer's support and ensure that future generations will be protected from the costs: emotional, societal, and financial.

Alex Turok is currently an M.B.A. candidate at Columbia Business School specializing in Healthcare and Pharmaceutical Management. Prior to business school, he worked for ZS Associates — a management consulting firm based in Princeton, NJ. His advocacy for Alzheimer's disease is inspired by his 86-year-old grandmother who is battling advanced dementia and cancer.

Alex received a B.S. in Applied Economics and Management from Cornell University.

How to Cope with Alzheimer's Now

For those of us with a family member diagnosed with Alzheimer's we know all too well the financial burden of this disease; and we cannot wait for policies to evolve over time, rather we need immediate help. The first step is to contact the Alzheimer's Association, learn about their legal and financial planning seminars, or meet with one of their care consultants. Review your loved one's finances and look for opportunities to cut costs. Be realistic about the available funds and make a plan for the future. Consider applying for government programs such as SNAP (food stamps) or Medicaid if the person has depleted their savings. Consult a tax adviser as the person with dementia may qualify as a dependent for income tax deductions. Seek the advice of an Elder Care attorney to plan and protect the person's assets for their spouse's needs. Take advantage of low-cost and free community services. And finally, brainstorm other forms of income such as the sale of personal property or leveraging the equity in a home through a reverse mortgage.



More than 5 million Americans are living with Alzheimer's disease.



In her 60s, a woman's estimated lifetime risk for developing Alzheimer's is 1 in 6. For breast cancer it is 1 in 11.



1 in 3 seniors dies with Alzheimer's or another dementia.



Every 67 seconds someone in the United States develops Alzheimer's.



Alzheimer's disease is the 6th leading cause of death in the United States.



In 2014, the direct costs of caring for those with Alzheimer's to American society will total an estimated \$214 billion.

Storming the Hill



Hillary Stuchin
Director of Public Policy
HStuchin@alznyc.org

This year's annual Alzheimer's Association Advocacy Forum brought more than 900 advocates to Washington, D.C. to learn about new Alzheimer's related legislation, meet with members of Congress, and make Alzheimer's disease a national priority. The main message of the 2014 Forum: the Alzheimer's crisis isn't looming — it's here.

The Advocacy Forum opened with the keynote address delivered by CNN's Candy Crowley. She shared her personal experiences as a caregiver for her mother. Among other insights, Crowley encouraged advocates to share their own stories with legislators and show them how close to home this disease can hit, especially when it comes to its rate of incidence in women. "Don't hesitate to make this a women's issue. You hear about the war against women, but for the grace of God is that congressperson with their mother, wife or daughter who could get the disease," said Crowley.

Forum attendees were also introduced to new proposed legislation and federal priorities focused on increased funding for research. The Alzheimer's Accountability Act (S.2192/H.R.4351) is a bipartisan effort to ensure that Congress has the information needed to set funding priorities and fulfill the goal of the National Plan to Address Alzheimer's Disease — effectively preventing and treating Alzheimer's by 2025. The Alzheimer's Accountability Act sets up a direct line of communication between Alzheimer's researchers and Congress.

This legislation works to support our current research funding request for \$200 million for Alzheimer's



NYC Chapter Ambassadors, Advocates, and Staff on Capitol Hill. We visited Rep Hakeem Jeffries (top right), Grace Meng (bottom left), Carolyn Maloney (bottom right), and many more.

disease. As the most expensive disease in America, nearly one-in-five Medicare dollars is spent on a person with Alzheimer's disease, and costs are set to skyrocket in the coming years. Without any effective treatment or a cure, Congress must make this investment to address this financial burden. Creating the means for regular direct reporting and communication between Congress and the National Institutes of Health (NIH) sets the stage for potential funding.

During our Capitol Hill meetings with lawmakers, the New York City Chapter, represented by Ambassadors, Junior Committee members, and staff, met with all 11 of our city's members of the House of Representatives and two Senators. In each meeting, members and staff met our requests with great support and encouragement. As advocates shared their personal accounts of caring for family members with Alzheimer's disease, the congressional staff was clearly moved by these stories, and often could relate to the challenges of caring for a family member or friend living with dementia.

The past few months have shown great growth for Alzheimer's

disease advocacy, outreach, and recognition. In January, President Obama signed an omnibus bill allocating an additional \$122 million to Alzheimer's research, care, and support services. In February, Dr. Francis Collins, Director of the NIH, Actor/Comedian Seth Rogan, and others testified before the Senate Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies, outlining the economic effects of Alzheimer's disease in America, and the current state of biomedical research into prevention and treatment. To that end, in June, the Senate Appropriations Subcommittee allocated an additional \$100 million in its fiscal year 2015 funding bill for Alzheimer's research to help keep us on course to find an effective treatment or prevention for Alzheimer's disease. Thanks to you, our advocates, lawmakers are finally starting to consider the impact and consequences of Alzheimer's disease on our country.

As we continue to meet with elected officials at the city, state, and federal levels, and compel them to address Alzheimer's disease, it is important that our advocates do the same.



Congratulations...

Lou-Ellen Barkan, NYC Chapter's President and CEO, celebrates her 10th anniversary. In appreciation and recognition, the Board of Directors presented her with a special gift created for the occasion, a one-of-a-kind hand-blown vase, created by glass artist Eric McLendon.

and thanks!

The Chapter thanks the staff for their extraordinary hard work up to and on the night of the 2014 "Forget-Me-Not" Gala. Our event would not be a success without them. Thank you!



There are more than 5 million Americans living with Alzheimer's. Are you one of the many who provide their care?

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New York's Caregivers Need Help

By Beth Finkel

Stretched, strained and stressed are the 4.1 million people who voluntarily take on the tremendous burden of caring for a relative who is ill, frail, or elderly. Dedicated to enabling their loved ones to age at home and not in expensive institutional settings, caregivers provide an estimated 2.68 billion hours of unpaid care per year at an estimated worth of \$32 billion. Conditions seem ripe for disaster with inadequate state support coming at a time when a looming demographic shift threatens to deprive future generations of this invaluable at-home care.

The New York State Office for the Aging (SOFA) estimates that unpaid caregivers provide the majority of all long-term care services to older adults and individuals with disabilities. Almost 25% of those providing care are aged 75 or older. The majority of the care receivers (85%) are aged 75 or older and average 82.3 years of age. Of those with at least one health problem, Alzheimer's or another dementia is the most prevalent condition.

SOFA and the network of county Area Agencies on Aging (AAA) support caregivers through several community-based programs. However, a review by AARP of the current SOFA budget reveals that less than \$3 million in state funds are specifically appropriated for programs focused on assisting caregivers. The insufficient funding has crippled these agencies' ability to provide adequate services.

Employers are also adversely affected by the strains on caregivers. A 2006 MetLife study found businesses lose as much as \$33.6 billion annually in worker productivity because of employees' caregiving obligations.

The present caregiving crisis has the potential to snowball into disaster if left unaddressed. Caregivers needs will only continue to mount as the number of New York families and neighbors providing help to frail individuals

grows. The current percentage of New Yorkers providing such support is now 32%, up from around 25% throughout the 1990s. The Baby Boom Generation, which currently makes up the majority of caregivers, appears doomed to run into future trouble when their turn comes to seek care. As the Boomers age, the younger people able to provide care for them proportionately decreases. A recent AARP report found that while there were 6.6 potential caregivers aged 45 to 64 for every person in the high-risk years of 80+ in New York in 2010, there will be only 4.8 in 2030 and 3.5 in 2050.

These shifting demographics in a state already ranking 4th in the nation in adults aged 60+ calls for an overhaul of the current state programs that fail to meet the needs of caregivers.

Caregivers' cries for help were heard loud and clear when, over the summer of 2013, AARP New York, NYS Coalition of Alzheimer's Association Chapters, the Council of Senior Centers and Services of New York City, Inc., the NYS Caregiving and Respite Coalition, and several organizations convened a series of 12 listening sessions across New York to hear directly from caregivers and service providers. The purpose was to learn about the challenges facing caregivers and to find ways to help family caregivers assist older adults in living as independently as possible and safely in their homes. Throughout these listening sessions, over 900 caregivers clearly articulated the services they require. After hearing what caregivers had to say, AARP formulated a series of policy recommendations for state legislators, aimed at revitalizing support for at-home caregivers:

Policy Recommendations:

- Establish a Community Care Navigator (CC Navigator) program that will direct caregivers

to the information, services, and supports they need.

- Provide adequate funding to SOFA for non-Medicaid-funded caregiver assistance programs that will help caregivers keep seniors living at home.
- Provide training and skill-building to help caregivers manage the various medical needs of their elderly loved ones.
- Strengthen family leave policies to protect workforce productivity and support policies prohibiting discrimination against working caregivers.
- Ensure access to competent legal assistance and protect the vulnerable from fraud and exploitation
- Promote and increase affordable housing options designed to enhance independence.
- Support volunteer models that build social networks using both peer-to-peer and intergenerational approaches.
- Encourage direct-care staff recruitment and retention

AARP urges New York's lawmakers to address the pressing need to support the dwindling number of family caregivers, already struggling to support their loved ones, before this crisis spirals out of control.



Beth Finkel is the State Director of the AARP New York State Office. She leads the development and delivery of the organization's community programs, advocacy, and information for its 2.5 million members age 50+ across the state.

Moving Beyond Gender in Alzheimer's Caregiving

By Carol Levine

The statistics in the Alzheimer's Association *2014 Alzheimer's Disease Facts and Figures* are clear and compelling. Almost two-thirds of Americans with Alzheimer's disease are older women, and women are 2.5 times more likely than men to provide full-time care for someone in the late stages of the disease.

Yet, as Sir Austin Bradford Hill, the father of the randomized clinical trial, commented, "Health statistics represent people with the tears wiped off." Statistics give us the big picture, aggregating millions of individual stories. Looking behind the statistics reveals a much more nuanced picture of family caregivers, among whom a sizable minority — an estimated 30 to 40 percent — are men. Even so, women still do more hands-on care than men.

Gender does not determine a person's capacity for caregiving. I learned this firsthand during the 1980s when I was working as a medical ethicist in the HIV/AIDS epidemic. I met many gay men, often ill themselves, who were taking care of their dying lovers and friends, sometimes with help from lesbian friends. I learned a lot about the many varieties of "family caregiving," but didn't appreciate that in the mainstream world women were expected to take on caregiving roles without question or consent. When my late husband suffered a traumatic brain injury in an automobile accident in 1990, doctors and nurses in a rehab hospital assumed that as his wife I would give up my job to be available all day, every day. Husbands in situations similar to my own were greeted with great respect when they showed up for short visits after work. And when I finally was able to take my husband home, I was told, "You're on your own now!" Not for the first time

in my life, I said, "This isn't fair!" Many personal stories offer a window into the experiences of men and women caring for someone with Alzheimer's disease. John Bayley's memoir, *Elegy for Iris*, about his wife, the philosopher and novelist Iris Murdoch, is a devastating description of her decline. Jerald Winakur's book, *Memory Lessons: A Doctor's Story*, chronicles a physician's experience caring for his father with dementia.

For me, one of the most meaningful writers in this genre is Arthur Kleinman, a psychiatrist and anthropologist. In a series of articles in *The Lancet* from 2009–2011, he wrote with love and candor about caring for his wife Joan, who died from dementia. But even earlier, in his 1988 book, *The Illness Narratives*, Kleinman wrote about the relatives and friends of chronically ill people who "sit in the same waiting rooms, and who even travel through the same land of limbo, experiencing similar worry, hurt, uncertainty and loss...." Because I knew so well the geography of that place, *Living in the Land of Limbo* was a natural choice for the title of my recently published anthology of fiction and poetry about family caregiving.

In deciding which poems and stories to include, I didn't consider gender (of the caregiver or the person needing care) or disease. I looked for good writing — stories and poems that gave new insight into family caregiving. Not surprisingly several of the selections focus on a person with Alzheimer's disease, often but not always a woman. More surprising, perhaps, many of the authors are men. In "We Are Nighttime Travelers," for example, Ethan Canin tells the story of an aging couple. Although the husband is blunt about no longer loving his wife, who sees imaginary prowlers, he finds a way

to recover their feelings for each other through nighttime walks. Raymond Carver's poem, "Where the Groceries Went," captures the day-to-day frustrations of a son who tries hard to please his memory-challenged mother but inevitably feels the brunt of her anger. Some of the female authors — Mary Gordon in "Mrs. Cassidy's Last Year" and Alice Munro in "The Bear Came Over the Mountain," for example — place caregiver husbands at the center of the story.

Memoirs and literature may be a harbinger of the future, when men's roles as family caregivers will be more expected, acknowledged, and supported. According to the AARP Public Policy Institute, the Caregiver Support Ratio — the number of potential family caregivers aged 45–64 available to care for people over the age of 80 — will drop from 7.2 in 2010 to 4.2 by 2030, and to 2.9 by 2050. Men will have to be part of the response to this demographic shift.

Young men are already more involved in child care and household maintenance than men of older generations. It will be more natural for them to take on caregiving roles for a spouse, partner, or parent than it has been for men brought up to see this as "women's work." But they, as well as the women who now carry the heaviest burdens of direct care, will need a lot of help not only from their friends, but also their communities, and medical and social service professionals. Family caregiving must be seen as a profoundly human experience, not a gendered one.

Carol Levine directs the Families and Health Care Project at the United Hospital Fund.



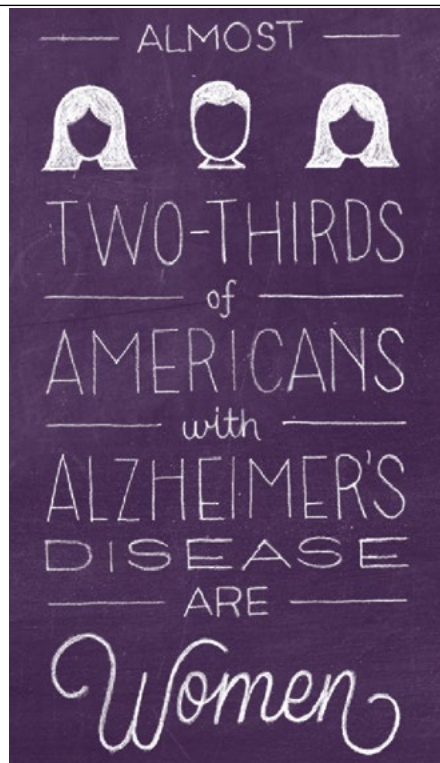
Carol Berne

Senior Vice President of Development,
Director of Leadership Giving
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“Women are at the epicenter of the Alzheimer’s crisis,” states the Alzheimer’s Association 2014 *Alzheimer’s Disease Facts and Figures* report. Some statistics about women are well known and others are rarely spoken about. Almost two-thirds of Americans living with Alzheimer’s are women. Women in their 60s are about two times more likely to develop Alzheimer’s in the rest of their lives than they are to develop breast cancer. And studies have consistently shown that women comprise up to 60% to 70% of Alzheimer’s caregivers.

Although the general public does not necessarily think of Alzheimer’s as a women’s issue, these statistics reflect what we see every day at the NYC Chapter. For example, 80% of the support group members are women, and over 80% of the more than 10,000 contacts to our 24-hour Helpline were women — wives, daughters, partners and friends.

Though you will be reading more about women and Alzheimer’s throughout this issue, I thought it would be of interest to focus on women and philanthropy, an area that has received far more prominence in recent years. According to the Women Gives 2012 report from the Women’s Philanthropy Institute at the Center on Philanthropy, Indiana University, which surveyed households headed by single females and single males, women are more generous in their charitable donations than men. The study found that women over the age of 50 give 89% more of their total income to charity than their male counterparts with similar socioeconomic backgrounds. Despite earning less than men, having less money in retirement savings and living longer than men, women at every income level are still likely to donate more frequently and a higher percentage of their income than men.



So why are older women more willing to give their money to charity? There are several factors, according to the Institute’s Director, including women being socialized to be the caregivers of their families and communities. Additionally, women and men have different motivations for giving, and that in previous studies, women scored much higher on traits such as empathy and caring, which affect giving to charity.

Research on women in philanthropy reveals that women are more drawn than men to causes that directly affect their lives and the lives of their families. So what does this mean for us? As we continue to build awareness for Alzheimer’s as a powerful women’s issue, and as we continue to distinguish the giving patterns of men and women, we will have all the right ingredients for successful fundraising — a compelling case for support, a predominance of women who use our services, and a growing number of women committed to supporting our cause. As always, please contact me at 646-744-2905 or cberne@alznyc.org if you would like further information.

Ways to Give

Giving by Check

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

Online/Credit Card

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

Appreciated Securities

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

Bequests

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

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

Life Insurance and Retirement Plans

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

Donor Advised Funds

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

Corporate Giving

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

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

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



Crissy Vicendese
Development Associate
CVicendese@alzny.org

On April 3, 2014, Director Emeritus Heath McLendon and his wife Judy hosted more than 50 guests at their Manhattan home for the second installment in our Innovations in Alzheimer's Research series. We were delighted to hear from Dr. Frank Gunn-Moore, of the University of St. Andrews, Scotland, who spoke about "Stopping our Brains from Shrinking: How an interdisciplinary approach and new technologies are changing the way we understand and treat Alzheimer's disease."

Dr. Gunn-Moore described some of the approaches that researchers are taking to understand the molecular mechanisms that are occurring in Alzheimer's and to develop potential new and novel drugs for its treatment. A highlight was the development of new technologies based on the



From left: Board Members Nathan Halegua and Jim Craigie; guest speaker Dr. Frank Gunn-Moore, Chapter Executive VP Jed Levine, Board Co-Chair Jeff Jones, and hosts Judy and Heath McLendon.

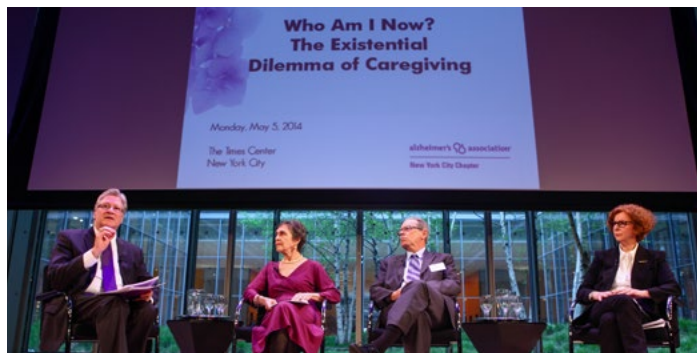
properties of light. In addition to NYC Chapter friends, we welcomed friends of St. Andrews University and the St. Andrews Society. The Innovations in Alzheimer's Research

series is designed to bring the latest in Alzheimer's disease research to friends and supporters of the NYC Chapter.



Barbara and Fred Kudish are joined by their son Matt (left), NYC Chapter's Senior VP of Caregiver Services, to celebrate the dedication of the Abraham Levine Early Stage Activity Corner, named in honor of Barbara's father. The space is in the heart of the Early Stage Community Room and is a place where early stage clients gather to socialize, support one another, enjoy a bite, and share their experiences.

Who am I Now? The Existential Dilemma of Caregiving



(from left) Jed Levine, Executive VP and Director of Programs and Services, moderates the discussion among panelists Alix Kates Shulman, Daniel Kuhn, and Sharon Shaw.



Trustees of the Charles Evans Foundation, Alice Shure and Bonnie Pfeifer Evans, are joined by Chapter staff, board members and panelists.

By James Campbell

Although change is inevitable in all parts of life, shifting from the role of spouse, daughter or son to that of caregiver is one of the most difficult challenges one can face. This particular change was the theme of *Who Am I Now? The Existential Dilemma of Caregiving*, the second annual Charles Evans Lecture on the Art and Science of Caregiving. The May 5th event, hosted by the Alzheimer's Association, New York City Chapter at the Times Center, consisted of a robust discussion on the complexities of caregiving.

In her introductory remarks, NYC Chapter President and CEO, Lou-Ellen Barkan spoke of the crisis of identity she faced while caring for her mother — and how NYC Chapter social workers helped her cope. She also drew attention to the Chapter's caregiver services, including the 24-hour Helpline and support groups, all offered free of charge. Following Barkan's introduction, Charles Evans Foundation Trustees Alice Shure and Bonnie Pfeifer Evans stressed the importance of supporting caregivers until a cure for Alzheimer's is discovered.

The event proceeded with moderator and Chapter Executive Vice President, Jed A. Levine, introducing

the distinguished panel: award winning writer and activist Alix Kates Shulman, whose memoir, *To Love What Is: A Marriage Transformed*, tells of her experiences caring for her husband; Daniel Kuhn, LCSW, a community educator and project manager for Rainbow Hospice and Palliative Care and author of *Alzheimer's Early Stages: First Steps for Families, Friends and Caregivers*; and Sharon B. Shaw, LCSW, CGP, who has worked as Support Group Leader Trainer and Clinical Supervisor for the Chapter since 2000.

The discussion mirrored the multiplicity of experiences related to caregiving, and each panel member drew on their expertise to shed light on, in the words of Levine, "[how] difficult, draining, exhausting and all encompassing" the role of caregiver can be. Caregivers' demands often cause them to shroud themselves in what Shulman described as "a veil" between them and the world. Kuhn went on to describe the dilemma of caregiving as both living in a world "rooted in the experience of dementia... but also... rooted in the world that requires memory and thinking." Living in both worlds "can break you, but it can also make you stronger."

So how does one cope with living in these two worlds? And how does

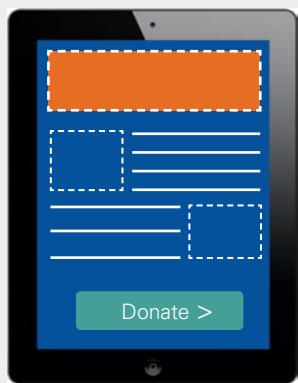
a caregiver turn frustration and exhaustion into resilience, strength and compassion for suffering? Shaw provided insight into these questions. Support groups, she said, "provide a very valuable outlet for members to talk about their experiences in a way that is not available to them in other settings." Shulman concurred, citing her support group as her most important resource.

The panelists continued to explore the intricacies of caregiving, delving into sexism, ageism, intimacy and even the power of music. During the final minutes of the conversation, they also touched on hope, including hope for an end to Alzheimer's, which, as Levine reminded the audience, is only possible through advocacy and investment in research.

James Campbell is a freelance writer based in New York City. He holds an MA in International Affairs and has written for various academic and human rights organizations, including the Anti-Trafficking Review.

Get Involved! Become a Chapter Champion

Your support of our mission means so much to us, and to the millions of people living with Alzheimer's. Make a difference in the fight against Alzheimer's.



Celebrate a Special Occasion With Us!

Let us design a project to celebrate your special occasion.

Birthdays, anniversaries, bar and bat Mitzvahs, graduations, weddings. All are opportunities to give something back. You can raise awareness, support the cause and make a special event more meaningful for you and your guests. We can help by designing a personalized website for your event. You can make a difference in the fight against Alzheimer's.

We Provide:

- **A Website** - your choice of a blog or webpage complete with a donation scroll to keep track of your progress
- **Marketing and Branding** - we will help you market your project, events, and any other ideas you might have to raise awareness and funds
- **Support** - we will do our best to help you hit the ground running from beginning to end

For more information and examples of our Chapter Champions, visit www.alznyc.org/champions

SAVE THE DATE

The Alzheimer's Association, NYC Chapter invites you to the
27th Annual Chapter Meeting

Early Diagnostic Tools and Prevention Studies: New Hope in the Global Fight Against Alzheimer's

Moderated by award-winning broadcast journalist, Dr. Max Gomez

Panel Discussion by three leading Alzheimer's Disease Researchers:

Richard Mayeux, MD, Taub Institute for Research on Alzheimer's Disease and the Aging
Brain, Columbia University Medical Center

Ralph A. Nixon, MD, PhD, NYU Langone Medical Center

Mary Sano, PhD, Alzheimer's Disease Research Center at Mount Sinai School of Medicine

Monday, October 27, 2014

The Times Center

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

RSVP By October 20, 2014

For more information, contact Crissy Vicendese at 646-744-2927
or visit www.alznyc.org/AnnualMeeting

2014 Forget-Me-Not Gala



Starting cornerback for the New York Giants, Prince Amukamara and his wife, Pilar.



Chapter staff assists Jamie Niven, Chairman, The Americas, Sotheby's, during the live auction.



Board member David Geithner and Board Co-Chair Jeff Jones.



Creative Leadership honoree, Dominic Chianese, and MC, David Hyde Pierce.



Greg Johnson and Charlene Maher from EmblemHealth, the recipient of the Community Leadership Award, with Gala Chair Jeff Gitlin.



Chapter Champion Rachael Bachleaa and her husband, Simon.

Honorees



Dominic Chianese, Victor Garber, Jason Daniele, Marin Mazzie and David Hyde Pierce.



Board member Jim Lavelle and family.



Auction Committee Chair, Janie Press, and Donald Gottheimer.



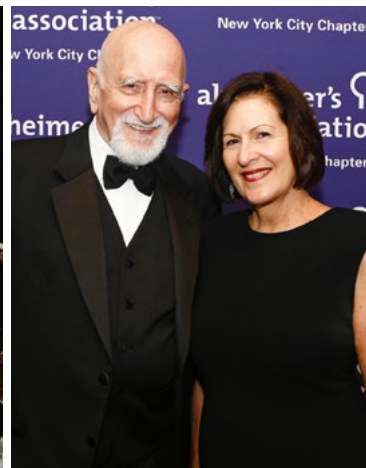
Board member Lori Oscher Friedman and husband, Eric Friedman.



Former JC President Erin Eininger and current JC President, Marielle Mindlin Bernstein.



Board member Jim Craig and guests.



Dominic Chianese and Chapter President and CEO, Lou-Ellen Barkan.



The 2014 Gala Silent Auction Committee with the Chapter Marketing staff.



Chapter Executive VP, Director of Programs & Services, Jed Levine with ABC's Bill Ritter.



New York City Chapter's Board members.



Drs. James Galvin, Peter Davies, Mony de Leon, Thomas Wisniewski, Mary Sano, Steven Ferris and Max Gomez



Board member Steve Boxer and Michelle Walker



Board members Susan Kayser and Marianne Dziuba-Fiore with husbands Sal Polisi and John Fiore.



Board member Elvira Bisignano and guests.

The Need for Early Stage Services



Matt Kudish
Senior VP of Caregiver Services
MKudish@alzny.org

There are many more gray areas than black and white when it comes to dementia. From the actual number of people living with the disease, to the ways in which symptoms manifest, to the age of onset, to the timing of transitions between stages, there is tremendous variability from one person to the next. As they say, if you have met one person with dementia, you have met one person.

There is, however, one aspect of the disease about which we are certain: all persons with dementia experience an early stage. This is the stage when symptoms can more easily be hidden or go unnoticed. The period during which persons affected and families alike can explain away the signs, and go on as if nothing is happening. This is the particular segment of the dementia spectrum when we are still able to look away and pretend, perhaps, that this is not our reality.

Every stage of the disease presents unique complications and challenges, and the early stage is no exception. In addition to the above, the early stage usually brings up strong feelings for everyone involved. Feelings of anger, denial, fear, and frustration are often just the tip of the iceberg.

But we know that people with early dementia are experiencing significant changes with enormous impact and that their need for normalization and support, even in this early stage, is crucial.

There is still a palpable stigma around dementia, which often prevents people from disclosing their concerns about their symptoms. This can lead to a delay in seeking diagnosis, and in exploring treatment options, including programs.

The need for services specifically for the person in the early stage is profound.

People with the disease deserve the opportunity to engage with others in social experiences where they can see they are not alone. The impact of knowing there are others going through something similar cannot be overstated. The programs the Chapter provides at our Harry and Jeanette Weinberg Early Stage Center provide people with early stage dementia opportunities for socialization in a supportive environment. Our clients can be with others without the pressure of remembering each other's names or the anxiety of recalling what was just said. The activities we provide in our Early Stage Center engage people in what they're able to do and their strengths, as opposed to focusing on their losses. We recognize — and our clients have taught us — the importance of creating as normal an environment and experience as possible.

Remember that in the early stage people are, in general, fairly independent. They still retain insight into their condition and many are seeking the opportunity to discuss their diagnosis. They are often looking to be actively engaged and to remain vibrant, contributing members of society. They are neither looking for, nor are they appropriate for, higher-need programs such as some adult day care settings or home care services.

Striking the balance between independence and support is paramount. We must work to sustain their independence and autonomy, while simultaneously creating situations where we add value to the individual's quality of life. Walking this line is most certainly an art and not a science.



So-called early stage programs exist in the community, however, in our experience, at least some portion of the clients served are usually further along in the disease process. This has serious implications. Put yourself in the shoes of the person with dementia in the early stage. Imagine apprehensively visiting a program to see if it's something in which you might be interested and seeing participants in the middle stage. More often than not, you're running for the door never to return. In order to maintain the integrity of the program, as a program for persons in the early stage it is critical to establish guidelines for participation, and to stick to those diligently.

As the number of people affected by dementia continues to increase, the need for programs throughout the city specifically designed for persons with early stage dementia is critical. We are proud that our Early Stage Center is an incubator for the development of best practices for working with persons in the early stage of dementia, and look forward to exploring ways to share what we have learned with the broader community to ensure the needs of this specific population can be met in the most effective and dignified manner possible.

For more information about our Early Stage Center, please call our 24-hour Helpline at 800-272-3900.

African American Outreach



Paula Rice
Manager, African American Outreach
PRice@alznyc.org

According to the Alzheimer's Association *2014 Alzheimer's Disease Facts and Figures* report, almost two-thirds of Americans with Alzheimer's disease are women, and more than 60% of Alzheimer's and dementia caregivers are women.

These factors are compounded in the African American community where older African Americans develop the disease at twice the rate of older whites. This community has higher rates of heart disease, hypertension and diabetes, which have been linked to Alzheimer's and other related dementias.

Combined, these factors fueled the creation of the Brain Awareness

Summit held on June 23rd at the Harlem State Office Building. The Chapter's African American Outreach program partnered with Councilwoman Inez E. Dickens and Congressman Charles B. Rangel to sponsor the event. The Summit addressed brain health in the African American community as well as caregiver wellness.

The summit consisted of a medical panel and a caregiver panel. The medical panel was comprised of experts from NYU Langone and Columbia University Medical Centers, Mount Sinai School of Medicine and Pfizer Inc. Experts from the Chapter and Center Light Health Care comprised the caregiver panel. Both panels were expertly moderated by Dr. Warachal Faison, Medical Director, Women's and Men's Health, Global Innovative Pharma Business at Pfizer Inc.

The panels provided the community with an open dialogue to discuss brain health from the perspective of cultural barriers, risk factors, early diagnosis and treatments. It also gave caregivers an opportunity to have a dialogue about caregiver stress and the importance of coping skills and respite.

As a result of the Alzheimer's Association *Facts and Figures* highlight on women, African American Outreach along with the support of our elected officials is focusing its efforts on encouraging women from the African American community's faith-based institutions, senior centers, community organizations and senior housing communities to be informed and get the help they need.

Latino Outreach



Roberto Reyes Jr.
Manager, Latino Outreach
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After reading the Alzheimer's Association *2014 Alzheimer's Disease Facts and Figures*, one can't help but feel disturbed. The information is overwhelming, and troubling.

What disturbs me most is the lack of knowledge about the disease in the Latino community. When I speak to Latinos I usually ask: "When I say the word 'dementia,' what is the first thing that comes to your mind?" Often the people I speak to become very quiet. In our culture, we don't like to speak about things that make us uncomfortable. We tend to be superstitious and seem to believe that not talking about it will prevent the onset of the disease from happening to us.

Our attitudes about Alzheimer's need to change because this is not a disease that only affects older people. In my tenure at the Chapter, I have noticed Latinos "magically" develop the disease. Too often I see Latinos requesting help from the Chapter when their relative is in the middle to late stages of the disease because they "just got diagnosed," even though the signs have been present for years. Many of the warning signs are attributed to the person "being set in their ways," or "ornery." As caregivers we make excuses for what we refuse to accept is unfolding before our eyes: 'it can't possibly be dementia, my mom remembers everything from the past as if it were yesterday in vivid detail,' but she can't tell you if or what she ate for breakfast.

The confidence we exude as a culture sometimes borders on arrogance, and it may not allow us to make the right decisions when it comes to our loved

ones. "I got this! I will take care of my mom and keep her home." "She took care of me and I will take care of her," "No one will take better care of her than me, I'm her daughter." These are just some of the phrases I hear daily. Our sense of duty can be blinding and overwhelming at times. There comes a point when the level of care exceeds what we as caregivers can provide. We cannot allow our sense of duty and pride to cloud our judgment when we make decisions about the care of our loved ones.

We are here to help. I speak in the community regularly and look forward to seeing you out there. If you would like more information please visit our website at www.alz.org/nyc. If you would like us to speak at your next meeting at your senior center, school, community board, etc., you can reach me at rreyes@alznyc.org or at 646-744-2935.

Trained Workforce in NYC



Matt Kudish
Senior VP of Caregiver Services
MKudish@alzny.org

We know the numbers. Ten thousand Baby Boomers turn 65 each and every day in the U.S.

And we know the risk. Aging is the most significant risk factor for developing dementia.

Put the two together and it is no surprise that in less than 40 years we will likely see a three-fold increase in the number of people living with Alzheimer's disease or a related dementia.

And this just represents the number of people living with the disease.

Let's not forget the fact that the majority of people living with dementia (not all but most) also have at least one person involved in their care, which at least doubles, essentially, the number of people affected by dementia.

What this means for us in New York City is that, by 2050, roughly one out of every five of us will either have the disease or be caring for someone who does. Disconcerting, to say the least.

Yet this is only part of the problem we face. Think for a moment about the types and amounts of care each person living with dementia will likely need over the course of his or her disease.

From food shopping and meal preparation to bathing, dressing, and eventually toileting, to the more advanced stage when assistance is required with all aspects of care including feeding and hydration, the needs of persons with dementia are broad and can be difficult to predict or anticipate. Add to this already complicated situation the

fact that communication changes cause additional challenges regarding engaging persons with the disease throughout its progression.

Even in the best of circumstances, providing this depth and level of care to the number of people we know will require it would be an enormous task. And, truth be told, we are not in the best of circumstances. Despite the fact that home care workers are the single largest workforce in New York City, the training requirements do not begin to address the complexities of quality dementia care.

It is worth noting that the standards of the New York State Department of Health around home care workers aim to prepare a workforce to address myriad issues affecting persons both young and old, with wide-ranging issues across the continuum of physical and cognitive impairments. Naturally this broad mandate will hardly be able to provide the deep dive necessary to address the complexities of the many diseases causing dementia. And how could it?

Good dementia care does not generally fit in neat, tidy boxes of "if/then" scenarios where one specific intervention will garner positive outcomes across a variety of situations. Good dementia care requires care providers to step into the world of the person for whom they are caring, and to see each person as a unique individual while honoring wholly the unique history, remaining abilities and longstanding preferences of the person receiving care. The ways in which we encourage caregivers — both professionals and family members alike — to communicate with the person for whom they care is very different from the ways in which we communicate with others in our lives who are cognitively intact. This level of care requires a new way of engaging, and new approaches to communication. And these skill-sets are not generally

innate in us. In fact, none of us is born with the knowledge and skills to provide the type of care a person with dementia will need throughout the disease trajectory, especially when the care is being provided to someone for whom we care deeply, whose decline is emotionally challenging for us to reconcile.

This is where the New York City Chapter's Dementia Care Training for Professional Caregivers comes in.

The Chapter trains nearly 300 direct care providers annually, and the number grows each year. Our training consists of a variety of topics including understanding dementia as a disease process, enhancing communication, managing behaviors and creating appropriate activities, as well as the significance of truly knowing the person receiving the care, and the importance of self-care for the caregiver. We provide a variety of tools for one's proverbial toolbox, empowering professional caregivers to address myriad issues across the continuum of the disease. Our training is changing lives. Certainly the lives of the persons receiving care and, just as importantly, the lives of the trainees in the room. When we have the knowledge and skills to do our jobs in the most effective and humane way possible, everything is better. Everyone wins.

Only when we accept the fact that the current system is unprepared to address the needs of this growing population can we begin to recognize and appreciate the unprecedented necessity of investing in this workforce in a profound and comprehensive way.

For more information about our Dementia Care Training for Professional Caregivers, please call our 24-hour Helpline at 800-272-3900.

Increase in Missing Alzheimer's Persons Incidents in NYC



Elizabeth Bravo Santiago

Manager, MedicAlert + Safe Return
ESantiago@alzny.org

As the population of the United States ages, more people are at risk for Alzheimer's disease and other age-related dementias.

If you have signed up to receive New York City Silver Alert Notifications you may have noticed an increase in the number of missing vulnerable adults. (To sign up go to www.nyc.gov/notifynyc). What you might not be aware of is the increase of incidents called into our emergency line by the New York City Police Department, thanks to Detective Michael McDonough who is working hard with the Chapter to increase awareness and ensure the safety of all older adults.

Even in the early stages of dementia, a person can become disoriented or confused for a period of time and become lost, including in familiar settings. The best definition that describes wandering is, "aimless or purposeful motor activity that causes a social problem such as getting lost, leaving a safe environment or intruding in inappropriate places."

Here are some warning signs a person with dementia might wander:

- Returns from regular walks later than usual
- Attempts to fulfill obligations such as going to work
- Talks about going home while at home
- Asks the whereabouts of past and current friends
- Fear arises from the misinterpretation of sights and sounds and even the urge to search for an object

Even if one has the most attentive caregiver, wandering can occur at any place and time.

With the increase of incidents over the last several months we have noticed that many persons with dementia are not enrolled in our program and have not reached out to receive any of our free services.

We cannot overstate how important it is for a cognitively impaired person to wear an identifier. MedicAlert® + Alzheimer's Association Safe Return® is a 24-hour nationwide emergency response service for individuals with Alzheimer's or a related dementia who wander or have a medical emergency. It provides 24-hour assistance, no matter when or where in the country the person is reported missing.

Concerned About Wandering?

Call our 24-hour Helpline at 1-800-272-3900 or visit us online at www.alz.org/nyc.

By enrolling, you will also be introduced to all our free programs and services held at the Chapter and what we offer in your community.

If you have not yet enrolled the person you are caring for please visit our website at www.alz.org/nyc and click the green box "Concerned About Wandering" and enroll online.

You can also call our 24-hour Helpline at 800-272-3900 with questions you may have concerning the care of someone diagnosed with Alzheimer's disease.



UNDERSTANDING DEMENTIA

What you need to know and where to go

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

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

Bicycles, Blondes & Brunettes!



Candace Douglas
Director of Constituent Events
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Spring has sprung and with it, our Athletes to End Alzheimer's (ATEA) have taken over New York City to do what they do best: raise awareness and funds in the mission to end Alzheimer's. For our teams, the month of May rolls in on bicycles in conjunction with the TD Five Boro Bike Tour. On that windy Sunday morning, 45 ATEA cyclists joined 32,000 of their closest friends to take over the car-free streets of NYC. They completed their 40-mile journey and raised over \$66,000 to support the Alzheimer's Association, NYC Chapter.

Our Bike Tour team continues to inspire and recruit from a diverse group of participants, with 2014 bringing in our youngest Athlete to End Alzheimer's ever. At age 12, Aaron Lesser, along with big sister and veteran teammate Emma, raised over \$4,000 as they rode in memory of their father who suffered and died with younger-onset Alzheimer's. Together, with all of our riders, they

personify the message that, no matter our age, everyone has a reason to end Alzheimer's.

Taking on the torch with the mission to "tackle" Alzheimer's in May, the 76 players and coaches of Blondes vs. Brunettes (BvB) had another fantastic year. Between the support of our incredible sponsors (Signmasters Inc., Modells, NYC Social, Copia NYC) and over 2,000 individual donations in support of players and coaches, the 2014 game raised a mighty \$121,000 and counting.

This year was the first time that BvB played under the lights at Octagon Field on Roosevelt Island. As the sun went down, and the lights came up, the intensity level of the game skyrocketed exponentially. After an evenly matched, tough four quarters, Team Brunettes emerged with their fourth victory in the NYC game, edging out the Blondes with a final score of 38-31.

At the end of the day, for our athletes, it is never about winning or losing any game or race, it is always about the fight against Alzheimer's. As Tracy Stevens, one of our cyclists,



Emma and Aaron (age 12) Lesser

puts it "Alzheimer's will not win if we each do a part — any part. So for every [activity you do] understand you do it with power and honor for each person impacted and their families."

Continue the fight with us by visiting www.alznyc.org/athletes or calling 646-744-2966.



Photo Credit: O'Sullivan Studios - All BvB Participants



*Kristyn Noeth
(Board Member &
BvB Co-Founder),
Liz Johnson,
Cassie Sklarz,
Melissa Dudra,
Colleen Richards
(BvB Co-Chairs)
and Lou-Ellen
Barkan*



*All Bike Tour
Participants*



This June marked the beginning of a new event for the Alzheimer's Association, NYC Chapter.

Playfully called Dyeing to End Alzheimer's, the mission aims to raise critical awareness and funds for our cause by asking participants to temporarily or permanently dye their hair purple during Alzheimer's & Brain Awareness Month. All participants, with the assistance of our event partner Ricky's NYC, are encouraged to go purple in as many ways as possible: purple hair, purple wigs, purple makeup, purple clothes, etc. The mission is to add visibility to a disease that is largely invisible, ignored, or not talked about in the public, as well as to decrease the stigma associated with memory loss.

This inspiring call to action asks our participants of all ages from the tri-state area to proudly sport their purple hair on subways, in parks, at work, and in their daily lives as a method to bring the battle against this disease front and center. Together, we will fight Alzheimer's disease, the nation's sixth leading cause of death, and we'll look good while we do it!

For more information, visit:

www.alznyc.org/purplehair

Photo Credit: Amy Y. Lee



Order before prices go up!
Don't miss the chance to dedicate a Bryant Park Chair
for just \$125

Prices will increase on October 1, 2014. Order your chair today!



Reserve Your Personalized Place in the Park

Don't miss the opportunity to recognize someone important in your life or the lives of others by dedicating a Bryant Park Chair in their honor. Today, there are more than two hundred iconic, green bistro chairs in Bryant Park dedicated to mothers, fathers, husbands, wives, sisters, brothers, friends, grandparents, aunts, uncles, and caregivers – all of whom share a connection to Alzheimer's disease. Prices will increase on October 1, 2014 so act now and ensure a beautiful personalized place in the park for someone special.

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

www.alznyc.org/bryantpark

Taking on Alzheimer's for our Future



By Marielle Mindlin Bernstein,
Junior Committee President

As young professionals trying to live in New York City, our pockets are already stretched thin, but that doesn't stop the members of the Junior Committee (JC) from doing our part to fundraise for the Alzheimer's Association, NYC Chapter. We all want to see a world without Alzheimer's and we know that we must do everything in our power to achieve that goal. We may not be at the stage in life where we can write very large checks, but what we can do is donate what our bank accounts allow and ask our friends, families, neighbors, and corporations to do the same. The side benefit of asking our networks to donate to our cause is that it inevitably gets the conversation started about Alzheimer's. And when one young person reaches out to their network to fundraise, it makes that many more young people feel comfortable to talk about the disease and to do the same.

The JC encourages our members to create their own fundraising campaigns, and member Barry



Williams did just that. This spring, Barry combined his passion for mountain climbing with his passion to end Alzheimer's and embarked on his Climb to ENDALZ. Barry's climb took him to Nepal to climb Island Peak (20,305') in the Himalayas, while raising thousands of dollars for the NYC Chapter and awareness for the disease. In his own words: "As the sun crested the ridge line of the mountains and I got my first glimpse of the peaks above the clouds, I was reminded of why I fight against Alzheimer's. So that, others and I can hopefully keep memories such as that sight as vivid for 60 years as they were that day."

In addition to inspiring personal adventures, the JC motivates our peers to fundraise by offering local events. On June 10th, the JC held our first annual Ride to Remember, a spin fundraiser at the up and coming Swerve Fitness cycling studio. Each rider was asked to fundraise and was given their own personal fundraising page to share their story and ask their family and friends for donations. In our inaugural spin event, our 43 riders raised over \$18,000! The spinning was



accompanied by snacks, smoothies, socializing, and pictures. All around the evening was a great success and lots of fun. We hope that you all decide to join us next year for our second annual event!

The Junior Committee's next big fundraiser is our signature event — the annual gala. Speakeasy Soiree will be a 1920's themed gala and will take place at the Harold Pratt House, a beautiful historic mansion on the Upper East Side. Save the date, Friday, September 19th, for a glamorous evening of exploring the mansion, dancing, sipping on cocktails, and bidding on silent auction items. Trust us, you do not want to miss out on this event! Get your tickets today at www.alznyc.org/speakeasysoiree.

As always, you can find out about what the Junior Committee is working on at www.alznycjc.org or www.facebook.com/juniorcommittee. We are always looking for new members and we encourage everyone to join us in our fight to END ALZ.



Summer/Fall 2014 Calendar

AUGUST

4 Monday

Legal & Financial Seminar

Time: 12:00 – 1:30 p.m.

Borough: Manhattan

7 Thursday

Understanding Dementia: What You Need to Know and Where to Go

Time: 12:30 – 2:00 p.m.

Borough: Queens

Note: This meeting is for family caregivers only.

Medicaid Home Care Seminar: A Practical Guide to the System

Time: 5:30 – 7:00 p.m.

Borough: Manhattan

Note: Prior attendance at a Legal & Financial Seminar is required.

8 Friday

Understanding Dementia: What You Need to Know and Where to Go

Time: 12:00 – 1:30 p.m.

Borough: Manhattan

Note: This meeting is for family caregivers only.

11 Monday

Educational Meeting

Time: 6:00 – 8:00 p.m.

Borough: Manhattan

Topic: Can Palliative Care Make A Difference For A Person With Advanced Dementia?

Speaker: Ann Wyatt, Residential Care Policy & Strategy Consultant, Alzheimer's Association, NYC Chapter

RSVP Online at www.alznyc.org/educationreg

12 Tuesday

Understanding Dementia: What You Need to Know and Where to Go

Time: 5:30 – 7:00 p.m.

Borough: Manhattan

Note: This meeting is for family caregivers only.

18 Monday

Legal & Financial Seminar

Time: 5:30 – 7:00 p.m.

Borough: Manhattan

20 Wednesday

Understanding Dementia: What You Need to Know and Where to Go

Time: 5:30 – 7:00 p.m.

Borough: Manhattan

Note: This meeting is for family caregivers only.

Understanding Dementia: What You Need to Know and Where to Go

Time: 1:00 – 2:30 p.m.

Borough: Brooklyn

Note: This meeting is for family caregivers only.

28 Thursday

Legal & Financial Seminar

Time: 5:30 – 7:00 p.m.

Borough: Manhattan

Please call our
24-hour Helpline at
800-272-3900

to register for meetings.

Registration is required.

Space is limited.

All meetings are free of charge and
subject to change.

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

You may notice that specific locations of upcoming meetings are not listed. You will receive location information during your registration call.

We wish to thank the following community partners:

CAPE at the Samuel Field YM-YWHA
Riverstone Senior Life Services

connect  culture®

Looking for a way to spend time with someone with dementia? **Check out Connect2Culture!**

Connect2Culture is the Chapter's cultural arts program which, in partnership with major NYC cultural institutions, provides meaningful activities for caregivers and persons with dementia. Visit a museum and explore art, participate in our We Sing! sing-along program, or dance with our ballroom partner Rhythm Break Cares at a social tea dance.

For more information about Connect2Culture, visit
www.alznyc.org/c2c

SEPTEMBER

4 Thursday

Understanding Dementia: What You Need to Know and Where to Go

Time: 12:30 – 2:00 p.m.

Borough: Queens

Note: This meeting is for family caregivers only.

Medicaid Home Care Seminar: A Practical Guide to the System

Time: 5:30 – 7:00 p.m.

Borough: Manhattan

Note: Prior attendance at a Legal & Financial Seminar is required.

8 Monday

Educational Meeting

Time: 6:00 – 8:00 p.m.

Borough: Manhattan

Topic: Early-Stage Dementia: An Insider's View

Speaker: Maureen Matthews, RN, PhD, Founder, To Whom I May Concern

RSVP Online at www.alznyc.org/educationreg

We Sing and Dance!

Time: 1:00 – 3:30 PM

Borough: Manhattan

Join us for an afternoon of singing and dancing!

Note: This event is for caregivers and people with dementia.

9 Tuesday

Understanding Dementia: What You Need to Know and Where to Go

Time: 5:30 – 7:00 p.m.

Borough: Manhattan

Note: This meeting is for family caregivers only.

10 Wednesday

Understanding Dementia for Professionals

Time: 3:00 – 5:00 p.m.

Borough: Manhattan

*Note: This meeting is **not** for family caregivers*

11 Thursday

Family Caregiver Workshop

Time: 12:00 – 2:30 p.m.

Borough: Manhattan

Note: This meeting is for family caregivers only and is a 4-part series. Please see box for more details.

12 Friday

Understanding Dementia: What You Need to Know and Where to Go

Time: 12:00 – 1:30 p.m.

Borough: Manhattan

Note: This meeting is for family caregivers only.

SEPTEMBER

12 Friday

Understanding Dementia: What You Need to Know and Where to Go

Time: 1:30 - 3:00 p.m.

Borough: The Bronx

Note: This meeting is for family caregivers only.

13 Saturday

Family Caregiver Workshop

Time: 10:00 a.m. - 3:00 p.m.

Borough: Manhattan

Note: This meeting is for family caregivers only and is a 2-part series. Please see box for more details.

15 Monday

Legal & Financial Seminar

Time: 5:30 - 7:00 p.m.

Borough: Manhattan

16 Tuesday

Placing Your Relative in a Nursing Home

Time: 5:30 - 7:00 p.m.

Borough: Manhattan

17 Wednesday

Understanding Dementia: What You Need to Know and Where to Go

Time: 5:30 - 7:00 p.m.

Borough: Manhattan

Note: This meeting is for family caregivers only.

Understanding Dementia: What You Need to Know and Where to Go

Time: 6:00 - 7:30 p.m.

Borough: Brooklyn

Note: This meeting is for family caregivers only.

18 Thursday

Legal & Financial Seminar

Time: 5:30 - 7:00 p.m.

Borough: Manhattan

19 Friday

Understanding Dementia: What You Need to Know and Where to Go - **IN SPANISH**

Time: 1:30 - 3:00 p.m.

Borough: The Bronx

Note: This meeting is for family caregivers only.

20 Saturday

Understanding Dementia: What You Need to Know and Where to Go - **IN CHINESE**

Time: 10:00 - 11:30 a.m.

Borough: Manhattan

Note: This meeting is for family caregivers only.

30 Tuesday

Family Caregiver Workshop

Time: 5:30 - 8:00 p.m.

Borough: Manhattan

Note: This meeting is for family caregivers only and is a 4-part series. Please see box for more details.

OCTOBER

1 Wednesday

Family Caregiver Workshop

Time: 12:00 - 2:30 p.m.

Borough: Manhattan

Note: This meeting is for family caregivers only and is a 4-part series. Please see box for more details.

2 Thursday

Understanding Dementia: What You Need to Know and Where to Go

Time: 12:30 - 2:00 p.m.

Borough: Queens

Note: This meeting is for family caregivers only.

Medicaid Home Care Seminar: A Practical Guide to the System

Time: 5:30 - 7:00 p.m.

Borough: Manhattan

Note: Prior attendance at a Legal & Financial Seminar is required.

6 Monday

Legal & Financial Seminar

Time: 12:00 - 1:30 p.m.

Borough: Manhattan

10 Friday

Understanding Dementia: What You Need to Know and Where to Go

Time: 12:00 - 1:30 p.m.

Borough: Manhattan

Note: This meeting is for family caregivers only.

14 Tuesday

Understanding Dementia: What You Need to Know and Where to Go

Time: 5:30 - 7:00 p.m.

Borough: Manhattan

Note: This meeting is for family caregivers only.

Family Caregiver Workshop

The Family Caregiver Workshop is a 10-hour education program devoted to the needs of the family caregiver. The workshop covers a number of topics including:

- Understanding cognitive, behavioral, and functional changes due to dementia
- Developing skills and strategies to enhance communication
- Problem-solving of common dementia-related behaviors
- Caring for the caregiver/practicing self-care

Attendance is required at all meetings during a workshop series.

Call our 24-hr Helpline at 800-272-3900 for workshop schedule.

15 Wednesday

Understanding Dementia: What You Need to Know and Where to Go

Time: 5:30 - 7:00 p.m.

Borough: Manhattan

Note: This meeting is for family caregivers only.

Understanding Dementia: What You Need to Know and Where to Go

Time: 1:00 - 2:30 p.m.

Borough: Brooklyn

Note: This meeting is for family caregivers only.

20 Monday

Legal & Financial Seminar

Time: 5:30 - 7:00 p.m.

Borough: Manhattan

20 Monday

Educational Meeting

Time: 6:00 - 8:00 p.m.

Borough: Manhattan

Topic: Middle Stage Alzheimer's 101

Speaker: Nancy Hendley, Dementia Care

Trainer, Alzheimer's Association, NYC Chapter

RSVP Online at www.alznyc.org/educationreg

21 Tuesday

Placing Your Relative in a Nursing Home

Time: 5:30 - 7:00 p.m.

Borough: Manhattan

22 Wednesday

Understanding Dementia: What You Need to Know and Where to Go - **IN SPANISH**

Time: 5:30 - 7:00 p.m.

Borough: Upper Manhattan

Note: This meeting is for family caregivers only.

23 Thursday

Legal & Financial Seminar

Time: 5:30 - 7:00 p.m.

Borough: Manhattan

27 Monday

Family Caregiver Workshop

Time: 5:30 - 8:00 p.m.

Borough: Manhattan

Note: This meeting is for family caregivers only and is a 4-part series. Please see box for more details.

28 Tuesday

Family Caregiver Workshop

Time: 12:00 - 2:30 p.m.

Borough: Manhattan

Note: This meeting is for family caregivers only and is a 4-part series. Please see box for more details.

29 Wednesday

Understanding Dementia: What You Need to Know and Where to Go

Time: 5:30 - 7:00 p.m.

Borough: Upper Manhattan

Note: This meeting is for family caregivers only.

alzheimer's  association®

New York City Chapter

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

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www.alz.org/nyc

646 744 2900

800 272 3900 — 24-hour Helpline

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EVERYONE HAS A REASON TO END ALZHEIMER'S.

WALK WITH US THIS OCTOBER!

Sunday, October 19, 2014

Riverside Park, Manhattan | 9:00am

Also, join us for our Walks in Brooklyn & Queens!



24-hour Helpline
800-272-3900

alznyc.org/walk

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