caringkind The Heart of Alzheimer's Caregiving

8

Issue 2, 2022

Meet Our Teen Board

(from left) Sarah Phillips, president Malcolm Furman Sophia Liu Eva Herrick

Teens Helping Teens

Also Inside:

Message from Eleonora

Introducing our Walk Chair

Cognitive Stimulation Therapy

caringkind

The Heart of Alzheimer's Caregiving

Issue 2, 2022 CaringKind Helpline: 646-744-2900 caringkindnyc.org 360 Lexington Avenue, 3rd Floor New York, New York 10017

Teens Helping Teens

The CaringKind Alzheimer's Teen Board is a group of dynamic youth leaders dedicated to raising awareness about Alzheimer's and dementia and caregiving. The Teen Board advocates for research funding, supports people with the disease and their families, and educates peers and future Gen Z leaders.

Too many teens have grandparents suffering from Alzheimer's and it is their mission to support caregivers and researchers to reduce the impact of dementia for future generations.



(from left) Sarah Phillips, president, Malcolm Furman, Sophia Liu, Eva Herrick

The Teen Board was recently profiled by PeopleTV for their efforts raising awareness about Alzheimer's and dementia. See the video here: <u>https://www.youtube.com/watch?v=rmU3p2NxFWA</u>

Some thoughts from the teen board on the impact Alzheimer's has on the family:

Eva: My grandmother had Alzheimer's. I had to learn patience regarding her repetition. And as a teen, the best thing you can do is to spend as much time as possible with that person. And supporting the people around you and talking about your experience.

Sophia: My grandmother has Alzheimer's. She speaks Cantonese and I don't, so it's a regret of mine that I can't easily connect with her. That said, it's really nice to know that there are so many other teens who have similar experiences.

Sarah: My grandfather has dementia. Seeing the dramatic transition that he's experienced through Covid from last year to this year is really scary. But it makes me appreciate the little things. My grandfather was a doctor and I plan on becoming a doctor, too.

Malcolm: My grandfather died of Alzheimer's when I was very young. Alzheimer's is the seventh leading cause of death – a truly disturbing statistic. I know many people and friends with family who have or had Alzheimer's and have experienced the challenges associated with caring for a loved one with Alzheimer's. I hope that we, as teens, can spread awareness and help to get more support for caregivers in the fight against Alzheimer's.

Last year, the Teen Board participated in the CaringKind Alzheimer's Walk and raised almost \$2,000 in support of Alzheimer's and dementia caregiving. If you'd like to support the Teen Board, you can find their 2022 Walk page at:

https://give.caringkindnyc.org/Teen-Board-2022

If you know a teen who would like to join, please go to <u>https://caringkindnyc.org/teens/</u>

Message from Eleonora Brain Health Awareness Month

by Eleonora Tornatore-Mikesh, CaringKind President & CEO



June is Brain Health Awareness Month; it's a month to help raise concern and awareness for Alzheimer's and how it impacts family caregivers. We are

launching our month with an amazing star-studded event. Even more special: a person with the disease is a featured speaker at our upcoming 26th annual **Gala** at the Pierre on June 6th.

Many exciting things are beginning to blossom at CaringKind. This year we added an element that will hopefully be a longgrowing group: **CaringKind Ambassadors**. Who is this group? It is a group of young professionals that have been impacted by this disease and are making efforts to help change the course and become connected.

I am often asked about how difficult it must be to hear these very hard stories about people losing their loved ones. The truth is that magic often happens when people connect with like-minded individuals, and they feel supported by each other. These bonds often result in life-long friendships.

A dear friend and recent widower said to me, "Its a club we wish we were not a part of, but we're glad we've joined so we don't have to be alone."

How can you help? This month, make a

commitment to get involved. It can be a post on social media reminding people about the importance of telling their story.

A caregiver shared this quote with me: "One day you will share your story of how you've overcome what you're going through now and it will become part of someone else's survival guide." The power of storytelling, whether at an event, a simple post on social media, or talking to a person at the grocery store, all become part of a bigger solution of support.

Learn more and visit our website on how you can become part of the solution, too!

Update On Cognitive Stimulation Therapy (CST)

Cognitive Stimulation Therapy (CST), an evidence-based program used around the world, creates a positive, accepting atmosphere where opinions rather than facts are shared and new ideas, thoughts, and associations are generated. CST activates various aspects of peoples' minds and its research shows improvements in cognitive function, mood, and quality of life.



We are mid-way through our first 16-week session. Here are some thoughts from two of our participants:

Q: Why did you enroll in CST?

Joanne: I was diagnosed with Fronttemporal dementia. I'm not working and I needed to keep myself going and preserve myself. I think it helps to delay the progression of the symptoms.

Ken: My wife learned about it and I joined.

Cheryl: We thought it would be valuable for him.

Q: What were your expectations before you went in?

Joanne: I thought it would be like a class, but it's better than that.

Q: What is your actual experience like, now that you've participated for a while? *Joanne:* CST is more structured than a class. One hour is perfect. I have somewhere to go and socializing with other people is helpful. The condition I have causes a lack of control and CST helps me monitor that. Ken: It's fun. We've got music, dancing, ideas from each other. We talk about our past. The music is my favorite part – I'm a motown person.

Q: Is life better for you since you started CST?

Ken: It's like having new friends, it's fun.

I like doing the group thing. They are wonderful - we're kind of from the same ilk. Joanne: I'm not working, so sometimes I still feel lonely. But CST cures that somewhat.

Q: What is your advice for people in the early stage of memory loss, dementia, or Alzheimer's?

Ken: Get involved. You're talking to other people like you who have the same background. And the social aspect of that is good. And kudos to the people who run the CST program – they're wonderful! I'd like to continue even after it ends. We hit it off!

Joanne: Look for support. Work on your condition. I'm in speech therapy which is also helpful.

Try to be as independent as possible. I was told that I'd need a nurse, but I've managed to live with my condition for more than a year and I work hard to be independent.

For more information on CST, please call our Helpline at 646-744-2900.

Meet Dr. Mauricio!

Dr. Mauricio Gonzales is our official Walk Chair for 2022. Follow him on Instagram: @dr.mauriciogonzalez



What relationship do you have to Alzheimer's and dementia?

Alzheimer's and dementia are rapidly becoming one of the biggest health care problems in the western world. Unfortunately, the Latinx community is one of the most common communities affected. This, as you well know, imposes a tremendous burden in the lives of the patients and their family members. As a medical doctor, I have come to understand that lifestyle plays a huge role in the prevention of different types of dementia. And this is paramount, as prevention is the only realistic tool we have nowadays.

Most of my patients understand the relationship between diet, exercise, low alcohol intake and diabetes, for instance. But most fail to see the significance of these important habits for my brain health.

And last, but not least, the mother of one of my dearest friends fell prey to Alzheimer's. I experienced first hand how disastrous this condition can be, physically and emotionally. I have taken the mission to educate my community on how to prevent dementias and boost our brain health.

How does it feel being named Chair of the CaringKind Alzheimer's Walk?

It is an honor, first and foremost. But after a few days, I realized it's also a big responsibility. This Walk is all about hope and awareness. But also, it's a reminder that it should be mandatory that we bring Alzheimer's and all dementias to the table when we discuss health care, especially among my community.

What inspired you to become a doctor?

My inspiration to become a doctor did not arise immediately. I always loved biology, pharmacology and physiology. But those interests do not represent the real life of being a doctor. Integrating all the knowledge into helping another human being is just a beautiful experience and something I feel truly privileged to do it daily. But this takes time. Today, I have taken the prevention aspect of medicine quite seriously as it is a powerful weapon against disease and human suffering.

You're a star on social media. How did that happen?

To be perfectly honest, I do not know. I have always liked to educate my community. I started giving talks about nutrition in undergrad, and I developed a keen sense to make complex topics digestible and meaningful. I think, when the whole boom of social media took off, it was easy for me to transition to these platforms as brevity and context are required. I also love to laugh and throw jokes and connect. My social media is all about actionable content, to stimulate a sense of community and dispel medical myths. And also, very important, to motivate folks to eat a plantcentered diet, exercise, and enjoy life. CaringKind Alzheimer's Walk: Brooklyn: September 25 Central Park: October 23 Walk with Dr. Mauricio! Join his team: https://give.caringkindnyc.org/Team-Dr-Mau

What are the top priorities for Latinx families facing an Alzheimer's diagnosis? It is truly daunting. We know that the family dynamics change when we have a family member that suffers from an Alzheimer's diagnosis. The top priorities include to help them navigate these tough times and train caregivers to understand this disease and educate relatives on how to confront the most common hurdles. Compassion and education, I would say are vital.

What is one achievable change that people can make today that will improve their brain health?

Oh, gee! We have plenty of data that shows that a diet the relies heavily on fruits, vegetables, legumes, nuts, olive oil, coffee, tea, and low in saturated fats can prevent so many cases of different types of dementia. It is worth noting that a plant-based diet has been shown to reduce the incidence of diabetes and obesity, which are important risk factors for cognitive decline.

Also, we have well designed studies showing the power of intense exercise that includes both cardio and strength activities, to reduce the velocity at which mild cognitive decline progress to dementias. Stress management, smoking cessation, cholesterol and blood pressure control are also core strategies. As you can see, there is plenty we can do. But we must act now. There is no time to waste.



Walkers at the 2021 Honor Wall, recognizing graduates of CaringKind's dementia training program.

CaringKind's

Free Live Webinars in July and August

Webinars are at Eastern Time, and in English unless otherwise specified.

July

August

Understanding Dementia July 8 10 am - 12 pm Legal and Financial

July 11 12 – 1:30 pm In Chinese (Cantonese): July 12 10 am – Noon

Medicaid Home Care July 7 5:30 - 7:00 pm

Monthly Education Meeting *Topic TBD* July 11 6:00 - 8:00 pm

Understanding Dementia August 12 10 am – Noon

Legal and Financial August 15 5:30 - 7:00 pm

Medicaid Home Care August 4 5:30 - 7:00 pm

Family Caregiver Workshop In Chinese (Mandarin) 4 days: August 8, 12, 19, 26 10 am - 1 pm

Monthly Education Meeting *Topic TBD* August 8 6:00 - 8:00 pm

Training

Dementia Care Training for Professional Caregivers July 6 – August 17 9:30–3:30 pm

Understanding Dementia for Professionals July 26 2:00-4:00 pm

Register here: www.caringkindnyc.org/unde-professional-rsvp

Register by calling the CaringKind Helpline: 646-744-2900

Ways to Give

Giving by Check Please make checks payable to CaringKind and mail to: 360 Lexington Avenue, 3rd Floor

New York, NY 10017

Online/Credit Card Visit <u>www.caringkindnyc.org</u> and click on Donate or call 646-744-2908. We accept

MasterCard, Visa, and American Express. Appreciated Securities

Gifts such as stocks or bonds may offer substantial tax advantages. Please speak to your tax advisor.

Bequests

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

I, ______ (first and last name, city, state, zip), give, devise and bequeath to CaringKind (or Alzheimer's Disease and Related Disorders, New York City, Inc.) with offices located at 360 Lexington Avenue, 3rd Floor, New York, New York 10017, (insert written amount of gift, percentage of the estate, or residuary of estate, or description of property) to be used for (insert "its unrestricted use" or name of CaringKind program).

Life Insurance and Retirement Plans CaringKind can be named a beneficiary of your retirement plan or insurance policy. Donor Advised Funds

If you have established a donor advised fund through another organization (e.g., community foundation, investment firm) you may recommend the award of a grant to CaringKind. Please check the guidelines pertaining to your donor advised fund. Corporate Giving

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

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

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

OUR MISSION

The mission of CaringKind is to create, deliver, and promote comprehensive and compassionate care and support services for individuals and families affected by Alzheimer's disease and related dementias, and to eliminate Alzheimer's disease through the advancement of research. We achieve our mission by providing programs and services for individuals with dementia, their family and professional caregivers; increasing public awareness; collaborating with research centers; and informing public policy through advocacy. Paid Advertisement

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Contact us today at (855) 553-7330 or email NIHStudy@silverbills.com