

Together, let's make healthy happen. Above the Advocate Aurora Health

Letter from the Medical Director - Darren Gitelman, MD

Dear patients, friends, families, and colleagues of the Advocate Memory Center:



Welcome to the Winter 2021 Edition of the Advocate Memory Center eNewsletter.

In this edition, we introduce Dr. Viet Le, our newest physician at the Center, and highlight the incredible story of how one of our patients developed new-found artistic abilities despite the effects of Alzheimer's disease.

Even though we are doing more in-person visits, we hope that telemedicine is here to stay for the health and convenience of our patients. In this newsletter we discuss how to have a successful

telemedicine video visit so that the patient and their medical provider can communicate most effectively.

Next we discuss the topic on everyone's mind... How to get a COVID-19 vaccine? The main take-home messages are that the currently available vaccines (Pfizer and Moderna) have turned out to be both highly effective and safe, and that there will be a vaccine available for everyone who wants one ... but it will take some time until there are a sufficient number of doses available. More information is available below, and many additional answers about the vaccines are available through Advocate's Health enews service.

The Memory Center continues to hold regular support groups via Zoom. This has been more important than ever given the stresses of the past year. Our social worker, Danielle Dodson, has also started a new **Grief Support Group** for family and friends who have recently lost a loved one to dementia, which has sadly been even more common this past year.

Although not discussed in this newsletter, many patients and their families have asked about the status of the drug, aducanumab, currently under review by the FDA for the treatment of early Alzheimer's disease. Although approval was initially supposed to be announced by March 7, 2021, the decision has now been delayed until June 7. More information about the drug, both positive and negative, are available through <u>Alzforum</u>. We will keep our patients updated as this situation develops.

We hope all our readers continue to stay safe and keep their spirits up. Thank you again for reading our newsletter,



Darren Gitelman, MD, FAAN, FANA Director of Cognitive Disorders, Advocate Medical Group Senior Medical Director, Advocate Memory Center

Advocate Memory Center Staff Highlights

Dr. Viet Le, DO, MS studied medicine at Lake Erie College of Osteopathic Medicine in Pennsylvania. He was a neurology resident and



chief resident at Garden City Hospital in Michigan. He completed a fellowship in behavioral neurology at the University of Cincinnati in Ohio in June of 2020. He joined the Advocate Memory Center team in September of 2020, and shares that "the opportunity to work alongside a multiprofessional team, including experienced physicians, neuropsychologists, social work, nurses, research and medical staff was too good to pass up!" He credits his former residency director, Dr. Pawlak, with his first true exposure to dementia. It was in this residency where he realized that caring for patients with dementia requires more than just medication adjustments, but also attention to safety in the

home and family dynamics. His wish to focus his career on behavioral neurology also stems from his personal experience with his grandmother. He shares that "It has been incredibly difficult watching my grandma go through this, but during my time with her, I have learned to be patient and listen rather than be critical. These experiences have urged me to better understand dementia, my grandma, and myself." As a provider, Dr. Le enjoys "providing current, evidence-based care to all my patients and working to ensure patients are empowered to make well-informed health care decisions." He is fluent in English and Vietnamese, and also working on learning Spanish and Mandarin Chinese. Outside of work, he practices kung fu and tai chi, and enjoys spending time with family and friends. Please join us in welcoming Dr. Le to the Advocate Memory Center! We are excited to add his extensive knowledge and talent to our team.

To find out more information about the Advocate Memory Center or to schedule an appointment, please see our <u>website</u>.

Patient Story: Doris Allen

By: Kathy Allen and Danielle Dodson, MSW, LCSW



Doris Allen never thought of herself as an artist. Born in Urmia, Iran, in 1939, Doris came to Chicago in 1960 with her siblings to start a new life. She married, had three children and devoted her life to caring and providing for her family. Doris had talents for sewing, gardening, and cooking, but most of all, she was a loving wife and mother. She also worked as a dental technician, painting porcelain crowns to precisely match the hue of patients' teeth...perhaps a foreshadowing of her later artistic accomplishments.

In late 2015, Doris was diagnosed with Alzheimer's by Dr. Gitelman, at the newly opened Advocate Memory Center. In 2016, she lost her husband to cancer. Her daughter, Kathy, assumed responsibility for Ms. Allen's care, with the assistance of in-home caregivers and the Advocate

Expressions Early Stage Memory Loss Program, where Doris enjoyed the art-based activities facilitated by the program coordinator, art therapist Angela Scalisi. As her Alzheimer's disease slowly progressed, Ms. Allen's ability to verbally express herself became more challenging. Then, as the country locked down and day programs such as Expressions closed due to the COVID-19 pandemic, the sudden isolation quickly manifested in behavioral changes and a steeper decline in Doris's ability to verbally communicate.

Struggling to work from home and care for her mother, and desperate to find ways to keep her mom's mind active while providing an outlet for self-expression, Kathy introduced Doris to a blank canvas and paint. In less than an hour, a masterpiece was created, and a talent that had gone unnoticed her entire life was discovered. The two developed a daily ritual, Kathy setting the canvas and paints in front of her mother, occasionally dipping a paintbrush into a color of Doris's choosing (just to get her started), and Doris creating a new work of art. She quickly amassed a collection of nearly 100 paintings. Equally as astounding as the transformation from blank canvasses

into beautiful masterpieces was the transformation Kathy witnessed take place in her mother. She describes Doris "laughing all the time" and engrossed in her painting - able to focus for several hours at a time.





Even after not being able to paint for several months due to hospitalization, rehab, and ultimately admission to a skilled nursing facility, Kathy shares that when she was finally able to visit Doris in the nursing home, "...just like that she knew exactly what to do with the paint brush!!"

Unfortunately, painting has not stopped the relentless progression of Doris's Alzheimer's disease. As Kathy shares, "as soon as [Doris] completes a painting, she has absolutely no recollection of what she has just created. She will stand back and look at her art and ask, 'Who painted that?' When I tell her she did, she just looks at me with complete amazement and says,

'When did I do that?' And that is the heartbreak of Alzheimer's."

And yet, so too is Doris's artwork the gift of Alzheimer's. For she has not only shared with her daughter a talent that was untapped for the majority of her life, but she has shared with our Center and our readers the powerful lesson that - despite the many real losses brought on by Alzheimer's - if we give a person the tools and opportunity, the attention and encouragement, they can share with us their stories, talents, identities, and gifts. And we are all richer for that.

To view more of Doris's art, visit https://mind-canvassing.com/. And next time you visit the Memory Center, allow yourself a couple of extra minutes to enjoy Doris's canvasses and other artwork mounted on the walls of our clinic. The Memory Center team's heartfelt thanks



goes to Doris and Kathy for their generous donation of three of Doris's paintings, and for their permission to share her story here.



Current Content: How To Have a Successful Video Visit

As mentioned in our last newsletter, as the COVID-19 pandemic continues, we continue to offer options for both in-person and telehealth (video visit) appointments with our providers. Many of you are likely adjusting to using technology as a means of staying connected with friends, family, and professionals. However, telehealth appointments with your medical provider may require more preparation than other remote visits or meetings. We offer the following recommendations to make the most of your telehealth appointment.

- Do a "dress rehearsal" before your appointment time. Test your internet connection, camera, and sound to be sure that all are in working order.
- Set your electronic device on a solid surface, such as a desk or table; do not hold your device during your visit, as this will make the picture unsteady.
- Make sure there is adequate lighting in the room so that your provider can clearly see you.
- Eliminate background noise by turning off the television and other devices, moving
 pets to another room in the house, and meeting in a private room with the door
 closed.
- Allow extra time to log on prior to the visit.
- Please be patient if your provider is running behind; technical difficulties can cause delays in the provider's schedule.
- Use headphones if you are concerned about privacy in your home.
- If you are unsure if a video visit will be appropriate for assessment of your current concerns, please call to inquire with your provider several days in advance of the appointment.
- For more ideas regarding preparing for video visits, please see the following articles:

Advocate Aurora Health eNews - How to Navigate a Virtual Doctor Visit

MedPage Today - Making Telehealth Visits Better for Nurses and Doctors

Resource Corner: COVID-19 Vaccine Information

As the COVID-19 vaccine becomes available to non-healthcare workers, AdvocateAurora seeks to keep you informed about vaccine news and distribution updates. Following is critical information regarding vaccination:

- The vaccines are at least 94% effective at preventing COVID-19.
- The risk of COVID-19 and its complications far outweighs the risk of getting the vaccine.
- We expect everyone who wants a vaccine will be able to get one in the next few months as large quantities become available.

For more information, visit <u>aah.org/vaccine</u>.

We understand that many people are eager to receive the COVID-19 vaccine for themselves and their loved ones. At this time, a dementia diagnosis alone does not place an individual in a higher priority group for the vaccine. However, persons aged 65 and above are

prioritized to receive the vaccine before others. The COVID-19 vaccine priority groups in Illinois are as follows:

Phase 1a

- Healthcare Personnel
 - Hospital settings
 - Non-hospital healthcare
 - Other congregate care
- Long-term care facility staff and all residents

Phase 1b (This is the current phase.)

- Persons aged 65 years and older
- Frontline essential workers
- Inmates
- Persons aged 16 to 64 years old with high-risk medical conditions (Persons aged 16 to 64 years old with medical conditions that increase the risk for severe COVID-19. Conditions include obesity, diabetes, pulmonary disease, heart condition including hypertension, kidney disease, cancer, immunocompromised, sickle cell and pregnancy)

Phase 1c

• Other essential workers (designation is fluid and may change) Timing is currently planned for late March.

Phase 2

• Rest of the population. Timing is currently planned for late May.

Source: Illinois Department of Public Health COVID-19 Vaccination Plan

As of 1/25/2021, Illinois has entered phase 1b of vaccine distribution. AdvocateAurora patients will be notified when they are eligible to schedule their vaccine via the LiveWell app. In order to be notified, it is critical that you download the LiveWell app and/or set up an online account at www.advocateaurorahealth.org/myadvocateaurora; for assistance with your account, contact the MyAdvocateAurora support team at 855-624-9366 or email myadvocateaurorasupport@aah.org. More information is also available at aah.org/vaccine.

If you are not a current AdvocateAurora patient, you can sign up with your county for local information about vaccine distribution roll-out. Procedures for notifying residents of distribution vary from county to county. While some counties are maintaining a registry, other offer updates via email for those who sign up. To find out how to stay informed regarding vaccine roll-out in our community, check the links below. If you do not see information for your county or town below, reach out to your county health department online or by phone.

- **Chicago:** The Chicago Department of Public Health does not currently offer a COVID-19 vaccine registry, but updates on vaccination sites should be provided at the following website as they become available: Chicago Vaccine Phases.
- Cook County (not including Chicago, Evanston, Skokie, Stickney, and Oak Park): Cook County COVID-19 Community Vaccination Program
 - Evanston: City of Evanston COVID-19 Vaccination Contact Form
 - **Skokie**: Village of Skokie COVID-19 Vaccination Information
- DuPage County: DuPage County Health Department COVID-19 Vaccine Registration
- Kane County: Kane County Health Department COVID-19 Vaccine Information
- Kendall County: Kendall County COVID-19 Vaccine Appointment Portal
- Lake County: Lake County Health Department COVID-19 Vaccine Registration
- McHenry County: McHenry County Health Department COVID-19 Vaccination Enrollment Form
- Will County: Will County Health Department COVID-19 Vaccination Registration

Alternatively, you can contact your local pharmacy to inquire about availability of the vaccine.

Advocate Memory Center Research Updates

The Advocate Memory Center is involved in a number of clinical trials. The following studies are open for screening. Please call us if you are interested in a study for youself or a loved one, or want to refer a patient (847) 720-6464.

Art Therapy Research Study: Study focused on examining the impact of art therapy on the relationship between patients and care partners

- Patients diagnosed with mild Alzheimer's disease
- Have a care partner who is willing to participate
- Study activities: 4 x 1.5 hour group art therapy sessions
- For more information call Danielle Dodson, (847) 720-6458

DIAN-TU: Study focused on participants at risk for, or having genetic forms of, Alzheimer's disease. (clinicaltrials.gov: NCT01760005)

- Patients with known mutations in PSEN1, PSEN2, APP genes
- Families with multiple generations of Alzheimer's disease with symptoms starting before age 60
- Enrolling into a Cognitive Run-in period (testing of thinking abilities)
 - No drug treatment is currently available, but when a drug becomes available, and if qualified, participants would have the first opportunity to join one of the study drug treatments
- Ages: 18 80
- For more information call Megon Holldorf, research coordinator, (224) 220-8133

U.S. POINTER: Two-year study that will test whether changing to one of two different lifestyle programs can protect memory and thinking. (clinicaltrials.gov: NCT03688126)

- Ages: 60-79
- Have a family history (parent or sibling) with memory loss or dementia or other risk factors such as high blood pressure, high cholesterol or early diabetes.
- Are not regular exercisers (generally less than 3 times per week)
- For more information, call Evelyn Torres, research coordinator, at (847) 720-6457

Advocate Memory Center - Research

Advocate Memory Center Support Programs

All Advocate Memory Center support groups will continue to operate via Zoom due to the ongoing pandemic. If you already receive email reminders for support group meetings, you will receive updates regarding how to join the meetings by Zoom or phone. If you do not already receive updates, please contact Danielle Dodson, MSW, LCSW (847.720.6458 or danielle.dodson@aah.org) to request to be added to the email list for the group in which you are interested.

NEW Upcoming Dementia Grief Support Group - The Advocate Memory Center, in collaboration with Advocate Aurora Hospice, will be piloting this support group for family and friends who have lost a loved one to dementia within the past 2 years. Start date to be determined; please contact Danielle Dodson if you would like to be kept informed regarding the development of this group.

Dementia Care Partner Support Group – For family and friends caring for individuals diagnosed with Alzheimer's disease or a related dementia. 1st Friday of each month from 10:30 am - 12:00 pm

Lewy Body Dementia Care Partner Support Group – For family and friends caring for individuals diagnosed with Lewy Body Dementia (LBD). 3rd Wednesday of each month, 2:00 - 3:30 pm

Younger Onset Dementia Care Partner Support Group – For family and friends caring for individuals diagnosed with any form of dementia at or before age 65. 2nd Wednesday of each month, 5:30 – 7:00 pm

Additional Sources for Support, Information, and Referrals

Advocate Older Adult Services Information and Referral: For information and guidance regarding both Advocate and non-Advocate resources and services for seniors. Leave a message and your call will be returned by a licensed social worker; 847.296.0737

<u>Alzheimer's Association Helpline</u>: Available 24 hours/day, 7 days/week for information about Alzheimer's disease and other dementias, referrals to local programs and services, and crisis support; 800.272.3900

<u>Illinois Department on Aging's Senior Helpline</u>: Information regarding state programs for older adults including Community Care Program (subsidized in-home care and other services for individuals with limited assets), home-delivered meals, and caregiver support; 800.252.8966

Future Newsletters

Thank you for taking the time to read this newsletter and stay connected with the Advocate Memory Center. Please feel free to let us know if there are topics you would like to see addressed in future editions. And, as always, please reach out if we can be of support to you, your family, your patients or clients.

Please send ideas, suggestions, links, etc. for future newsletters to Danielle Dodson, MSW, LCSW: danielle.dodson@aah.org.

Donate to Support the Memory Center

If you have found this newsletter, or other services of the Advocate Memory Center, to be beneficial, we would be grateful to receive your support at the "Donate" link below.

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