



WE DID IT!

10,000 Dementia Friends in Pennsylvania by December 2022!

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Breaking News

New Drug in Clinical Trials
Gives Encouragement

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Meals on Wheels of the Greater Lehigh Valley

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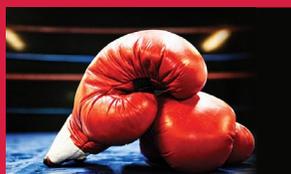
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SAVE THE DATE: THURSDAY, APRIL 27, 2023



**2023 Phoebe Institute on Aging (PIA)
Conference at DeSales University**

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Breaking News

President
Update



Sent September 27, 2022

We have an exciting major development about the potential for a new treatment for Alzheimer's-disease, and we wanted to share the positive results with you as quickly as possible.

Tonight, initial clinical-trial-results were announced for a drug called lecanemab which was tested in individuals living with mild-cognitive-impairment (MCI) due to Alzheimer's-disease and mild-Alzheimer's-dementia. Results from the clinical-trial found that this treatment-significantly-reduces-clinical-decline-from-the-disease.

These are the most-encouraging results in clinical-trials treating the underlying causes of Alzheimer's to date. These results indicate lecanemab may give people more-time at or near their full abilities to participate in daily-life, remain independent and make future healthcare decisions.

We will know more at the end-of-November when the data behind these initial results will be public. We look forward to learning more at that time about participant safety and representation in the trials. It's also important to manage our own expectations that this treatment is not yet Food and Drug Administration (FDA) approved and is not yet available in doctors' offices.

This is a major milestone for Alzheimer's-disease-treatments. It is a significant gain for people with the disease and their families and it further positions us to advance our mission in new and exciting ways.

We have never been more hopeful, and we hope you share our excitement. Even with the success announced today, we must redouble efforts to discover new targets and test new and more-effective treatments for Alzheimer's and all other dementia.

Thank you for all that you have done, all you are doing, and all you will do to make this a reality.

Joanne Pike, DrPH
President



NIA statement on report of lecanemab reducing cognitive decline in Alzheimer's clinical trial

By Richard J. Hodes, M.D., Director, National Institute on Aging (NIA), National Institutes of Health

October 03, 2022

Pharmaceutical companies Eisai and Biogen recently announced data for a phase 3 Alzheimer's disease clinical trial. The results show that lecanemab, an anti-amyloid antibody, slowed the rate of cognitive decline by 27% in an 18-month study involving participants experiencing the early stage of Alzheimer's. The incidence of adverse events was 21.3% for those who received lecanemab and 9.3% for those who received a placebo. About 25% of the U.S. participants in this study were Hispanic and African American.

The NIH National Institute on Aging (NIA) eagerly awaits publication of the data in a peer-reviewed scientific journal. Potentially promising outcomes such as this one are the result of sustained public investment in medical research, the tireless work of scientists around the world, and the help of people living with Alzheimer's and their caregivers. Although NIA did not fund the lecanemab study, our decades of research paved the way for this Alzheimer's trial that notably met its primary and secondary endpoints.

Specifically, NIA funding was integral to helping us understand the role of amyloid, the protein targeted by lecanemab. We supported a wide variety of investigations that led to the discovery of many candidate antibodies that were the basis for immunotherapies such as lecanemab and helped translate those findings into potential treatments. Additionally, the selection of participants for lecanemab clinical trials hinged on amyloid PET imaging, a technology that was developed with publicly funded research conducted and funded by NIA.

NIA is currently funding two trials to evaluate lecanemab's effectiveness at treating different types of Alzheimer's disease and related dementias. Through its AHEAD 3-45 Study, researchers will test the safety and efficacy of lecanemab on participants who have varying amounts of amyloid pathology, but do not yet have levels of cognitive decline to warrant a dementia diagnosis. One group, called A3, will involve participants who have intermediate levels of beta amyloid as seen on brain scans. Another group, called A45, will include participants who have elevated levels of beta amyloid.

Through the NIA Dominantly Inherited Alzheimer Network Trials Unit (DIAN-TU), researchers will use lecanemab in combination with another drug, E2814 in participants who are genetically susceptible to early-onset Alzheimer's, a rare form of the disease that typically occurs in a person's 30s to mid-60s. E2814 is designed to counteract harmful versions of tau, another hallmark protein associated with Alzheimer's. The researchers will evaluate the effects of E2814 alone, lecanemab alone, and the combination of the two drugs.

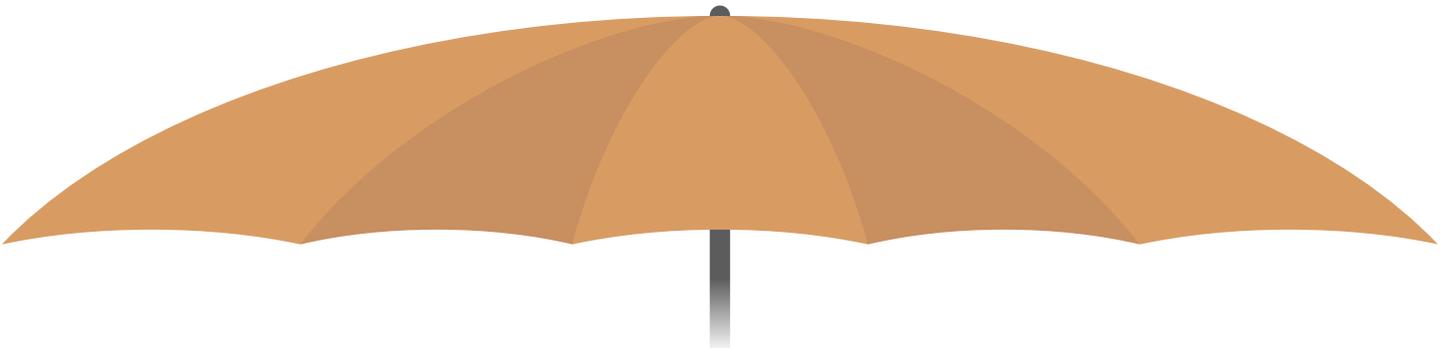
These efforts and many others can only happen in collaboration with the research community, industry, and importantly, public participation. NIA is grateful for the many individuals who have participated in



clinical trials that helped advance knowledge, and we continue to emphasize the enormous importance of participating in research studies. We remain committed to recruiting and retaining a broad range of clinical trial participants from diverse communities, and to expanding and diversifying the Alzheimer's and related dementias research workforce.

NIA-funded scientists will also continue to identify and test new dementia drug candidates, advance comprehensive models of care, develop new biomarker tests, explore disease risk and possible protective factors throughout the life course, examine disparities in dementia prevalence and care, and improve the understanding of the role of genetics and other disease mechanisms.

Search for New Umbrella Relationship for DFLV



Dementia-Friendly Lehigh Valley and the United Way of Lehigh Valley will amicably dissolve their relationship effective January 1, 2023. This is a sign of the growth and evolution DFLV has experienced over the last 10 years. A search team dedicated to leading DFLV through the process of identifying the "right" new umbrella relationship for DFLV has been assembled and consists of: Kelly Carney, Brynn Buskirk, Sandy Massetti, Wendy Scott, Kim Melusky, Donna Zimmerman, Laurie Greco and Sally Schoffstall.

This change will be a new chapter for DFLV and will require funds to cover the costs associated with making a transition, while ensuring the continuity of services and support DFLV provides in our community.

Your help is needed!

Please make a donation at <https://www.unitedwayglv.org/donate>. (Be sure to designate your donation is for Dementia Friendly Lehigh Valley in the designation field on the form.)



More than a Meal

by Monica McCandless, Director of Client Services



Meals on Wheels of the Greater Lehigh Valley provides meals to homebound and disabled individuals who cannot obtain or prepare a nutritious meal due to a medical condition. Our daily “Wellness Check” is the value-add that makes our services unique, especially for loved ones who are home alone and dealing with issues such as dementia. It’s what makes us so much “more than a meal.” Our clients and volunteers form relationships, both enjoying the daily connection. The

volunteers report any change in status or condition of our clients to the office upon making a delivery and, in turn, we report any concerns to family members, giving them peace of mind.

Volunteers deliver over 800 daily hot meals, or a combination of hot and cold meals, depending on the individual nutritional needs of a client, directly to the client’s residence every weekday. Clients who cannot be home to receive daily meal delivery—due to dialysis, or other therapies—may opt to receive weekly frozen meals.

Did you know Meals on Wheels has medically tailored meals? They include soft, pureed, lactose intolerant, and renal diets. Additionally, our staff will tailor meals to a client based on individual food preferences by substituting certain meal components that the client will eat.

To participate in our program, clients must be over the age of 18 years. Clients do not need to be low income to receive our service; clients of all income ranges are eligible. Meal cost is based on a sliding scale and cost can range from \$6.70 to \$10.70 per meal. Once a client is assessed for meal service, the start time can be within 2 working days. A 2-week payment is required to start services. Meals on Wheels requires a minimum of 3 delivery days per week. Our case managers will conduct an initial assessment of the client prior to starting services. They may assist in connecting the client with other services.

Meals +

What does **Meals+** mean? It means additional services offered through Meals on Wheels of the Greater Lehigh Valley. We mean it when we say that we are more than a meal!

1. Personalized grocery shopping at Giant stores
2. Delivery of Senior Food Boxes (a Second Harvest program) by MOWGLV volunteers



3. Food pantry project: Extra pantry items delivered to the client by volunteers and in partnership with eight local food pantries
4. Chef Pack-Frozen meals: for clients who are not ready for a daily meal delivery, don't feel like cooking for themselves, or who need some short-term meal assistance.
5. Ani-Meals: pet food delivered to clients to support their companion animals
6. "Welcome Bags" delivered to new clients who have been on our services for a month

If you are interested in receiving Meals on Wheels or have any questions, please contact our office at 610-691-1030, a Client Services Representative would be more than happy to help you.

An Update from the Professional Education Workgroup

The Professional Education Workgroup of DFLV is continuing work on its 2022 Strategic Plan. The mission of this workgroup is to enable the community to better support people living with dementia and their caregivers. Two of the workgroup's objectives are well underway.

The workgroup's first objective is collecting contact information on faith-based communities in Lehigh and Northampton counties. The goal is to reach out to leadership within each organization to offer training to help leaders identify members who may be living with dementia. Then, develop communication strategies to support their continued involvement in the community. To date, over four hundred faith-based communities have been identified and cataloged. Training, likely in virtual delivery, is planned for the third quarter of 2023.

The workgroup's second objective is to provide training on dementia awareness, communication strategies and helpful referrals to Emergency Medical Service professionals in the Lehigh Valley. Because of the nature of their work, EMS staff often have contact with people living with dementia in particularly stressful situations. Building awareness, easing communication, and assisting EMS professionals by teaching them how to obtain additional assistance and resources they need, will enable them to provide additional support for people living with dementia. A new member of the Professional Education Workgroup, with expertise as a First Responder, as well as other community partners, have been engaged to review materials for possible use in the training. It is anticipated this training will be available on-line, to avoid staff scheduling issues, during the first half of 2023.



Announcing Dementia Friendly Pennsylvania

On September 21, World Alzheimer's Day, the Jewish Healthcare Foundation announced the establishment of Dementia Friendly Pennsylvania, a new initiative aimed at

supporting Pennsylvanians living with dementia. Pennsylvania has joined the growing coalition of dementia-friendly communities across the U.S. by joining the Dementia Friendly America network.

Dementia Friendly Pennsylvania is a collaborative effort with Dementia Friends Pennsylvania, a program of the Jewish Healthcare Foundation, eight existing dementia-friendly Pennsylvania communities, and supported by the Pennsylvania Department of Aging. This initiative works to ensure communities across the country are equipped to support people living with dementia and their care partners.

"As Pennsylvania's older adult population continues to grow, we are seeing the incidence of lives impacted by Alzheimer's Disease and other dementias also increase. Dementia Friendly Pennsylvania will help raise awareness and increase understanding in our communities so people affected by the disease can be supported and enabled to live their best quality of life," said Secretary of Aging Robert Torres. "The Department of Aging is proud to partner in this effort to create positive environments and outcomes for older adults living with dementia."

More than 400,000 people in Pennsylvania are living with dementia. For every person diagnosed with dementia there are at least 3-4 people, which may include family, friends, and colleagues, whose lives are profoundly affected.

Dementia Friendly Pennsylvania will focus on encouraging the creation of dementia-friendly communities across the Commonwealth. A dementia-friendly community is one that is informed, safe, and respectful of people living with dementia and their families. Communities take action by leveraging tailored resources for businesses, faith communities, health care communities, first responders, legal and financial services, libraries, and multiple other community sectors. Additional goals include developing a website with statewide resources designed for people living with dementia, care partners, and professionals, raising awareness about dementia and transforming attitudes, and promoting meaningful participation in community life.

To learn more about Dementia Friendly Pennsylvania or become involved in the initiative, please email info@dementiafriendlypa.org or visit <https://www.facebook.com/dementiafriendlypa>

Dementia Research & Data

Research on Sleep & Bedtime...Are they putting us at risk for dementia?

Scientists and researchers continually try to find what makes some people more at risk for cognitive decline than others. Research published in Medscape Medical News, makes the connection between the amount of sleep we get and the time we go to bed, with our risk for dementia.



Long Sleep, Turning in Early May Up Risk for Dementia

Batya Swift Yasqur, MA, LSW, October 3, 2022. Medscape Medical News © 2022 WebMD, LLC

Too much sleep and time in bed (TIB) may raise the risk of developing dementia and Alzheimer's disease (AD), new research suggests.

Results from a population-based study of almost 2000 older adults, all of whom were free of dementia at baseline, showed that risk for dementia was 69% higher in those who slept more than 8 hours daily vs 7 to 8 hours daily; and it was twice as high for those who went to bed before 9 PM vs at 10 PM or later.

These associations were most pronounced in people aged 60-74 years and in men, the researchers report.

"Our study shows that self-reported sleep problems, such as long TIB and early sleep timing, are independently associated with incident dementia and AD in Chinese rural older adults, and their associations with greater global cognitive decline vary by age and sex," Rui Liu, MD, Department of Neurology, Shandong Provincial Hospital, Shandong University, Jinan, China, and colleagues write.

"This suggests that cognitive function should be monitored in older adults who report prolonged TIB and advanced sleep timing," they add.

The findings were published online September 21 in the Journal of the American Geriatric Society.

"Poorly Understood" Association

The researchers note that sleep quantity, quality, and circadian rhythm change as individuals age.

Previous studies have suggested that extreme sleep duration, sleep fragmentation, and excessive daytime sleepiness are associated with cognitive decline or dementia. However, the association of TIB — a composite indicator of sleep duration, latency, and fragmentation — with dementia is "poorly understood," the investigators write.



The longitudinal association of sleep timing with dementia and cognitive decline in older adults “has rarely been explored,” and most studies have investigated White populations in North America and Europe rather than rural adults in China, the investigators note.

It is additionally unclear whether sleep problems are associated with cognitive phenotypes that vary by demographics and APOE genotype.

To investigate these questions, the current researchers assessed a cohort of 1982 rural-dwelling Chinese older adults (mean age, 70 years; 59.6% women; 38.2% with no formal schooling).

Participants were drawn from the Shandong Yanggu Study of Aging and Dementia. Included were older residents in the western Shandong Province who underwent interviews, clinical examinations, and laboratory tests in late 2014.

Survivors of that cohort participated in a follow-up examination between March and September 2018 as part of the baseline assessments of the MIND-China study.

Sleep characteristics were assessed using the Chinese version of the Pittsburgh Sleep Quality Index and the Epworth Sleepiness Scale. Global cognitive function was assessed using the Mini-Mental State Examination (MMSE).

Participants were divided into the following tertiles, based on their sleep parameters:

Sleep Parameter	Definition
Duration	Short: < 7 hours Normal: 7-8 hours (reference) Long: > 8 hours
Time in Bed	Short: < 8 hours Normal: 8-9 hours (reference) Long: > 9 hours
Bedtime	Early: before 9 PM Middle: 9 PM-10 PM Late: 10 PM or later (reference)
Rise Time	Early: before 5 AM Middle: 5 AM-6 AM (reference) Late: after 6 AM
Mid-sleep time (the midpoint between bedtime and rise time, a proxy for circadian phase)	Early: before 1 AM Middle: 1 AM-1:30 AM (reference) Late: after 1:30 AM
Sleep latency (the time it takes to fall asleep at night)	Long: > 30 minutes
Sleep efficiency (percentage of time spent on sleep while in bed)	Low: ≤ 85%

All were followed for an average of 3.7 years. During this time, 97 developed dementia, including 68 with AD.



Selective Survival?

After adjusting for the confounders of age, sex, education, body mass index, alcohol consumption, smoking, hypertension, diabetes, dyslipidemia, coronary heart disease, stroke, and APOE genotype, results showed that long TIB and mid-sleep time were significantly associated with increased dementia risk, with a linear association between bedtime and dementia risk.

Every 1-hour advance in bedtime was associated with a 25% increased risk for dementia (95% CI, 1.03 - 1.53). Every 1-hour advance in bedtime and mid-sleep time was associated with an adjusted hazard ratio (HR) of 1.27 (95% CI, 1.01 - 1.59) and 1.49 (95% CI, 1.05 - 2.12), respectively.

The following table shows the fully adjusted HRs when sleep parameters were categorized into tertiles:

Outcome	Baseline Sleep Parameter	HR (95% CI)	P Value
Incident dementia	Long (vs normal) sleep duration	1.69 (1.01 - 2.83)	< .05
Incident dementia	Early (vs middle) bedtime	2.17 (1.22 - 3.87)	< .01
Incident dementia	Early (vs middle) mid-sleep time	2.00 (1.23 - 3.24)	< .01
Incident AD	Early (vs middle) bedtime	2.25 (1.12 - 4.50)	< .05
Incident AD	Early (vs middle) mid-sleep time	2.51 (1.45 - 4.34)	< .001

“Among individuals who were free of dementia at follow-up, baseline long TIB, early bedtime and mid-sleep time, early and late rise time, and prolonged TIB and advanced bedtime and mid-sleep time from baseline to follow-up were associated with a greater decline in MMSE score ($P < 0.05$),” the investigators report.

“Long sleep duration has been associated with global brain atrophy, more white matter hyperintensities, and proinflammatory biomarkers (eg, interleukin-6 and C-reactive protein), which may be the pathways linking long sleep duration to dementia,” write the researchers.

The age-varying associations of long TIB, early and late rise time, and early mid-sleep time with greater cognitive decline are “unknown,” they add. However, “selective survival may play a part in age-dependent associations because older age and sleep problems are both associated with mortality.”

Study limitations cited include the use of self-report, which may be subject to recall bias, and confounders not accounted for, such as sleep apnea.



Too Much, Too Little Sleep

Commenting for *Medscape Medical News*, Percy Griffin, PhD, director of scientific engagement at the Alzheimer's Association, noted that although **previous studies** have shown associations between shorter sleep duration and cognitive decline, the current study showed an association with longer sleep time.

It "adds to our understanding of the importance of sleep and how it may impact the risk of developing cognitive decline as we age. The study is telling us that too little or too much sleep might be bad for cognitive health," said Griffin, who was not involved with the research.

However, he cautioned that more work is needed, adding that "although interesting, there are some limitations to this study, including small sample size, self-reporting on sleep parameters, and the diversity of participants. "Future research should "also ask questions about the quality of sleep and use more objective measures," Griffin said.

The SYS-AD Study was funded by the Science and Technology Program for Public Wellbeing of Shandong Province, China. MIND-China was funded in part by grants from the National Key Research and Development Program of China, the National Natural Science Foundation of China, the Academic Promotion Program of Shandong First Medical University, the Taishan Scholar Program of Shandong Province, the Integrated Traditional Chinese and Western Medicine Program in Shandong Province, and the Brain Science and Brain-like Intelligence Technology Research Projects of China. Grants to individual investigators are listed in the original article. The investigators and Griffin have reported no relevant financial relationships.

Batya Swift Yasgur, MA, LSW is a freelance writer with a counseling practice in Teaneck, NJ. She is a regular contributor to numerous medical publications, including *Medscape* and *WebMD*, and is the author of several consumer-oriented health books as well as *Behind the Burqa: Our Lives in Afghanistan and How We Escaped to Freedom* (the memoir of two brave Afghan sisters who told her their story).



Caregiver Corner

Stress Leads to Burnout!

No doubt caring for another person is one of the most rewarding professions there is. But it doesn't come without risks. The physical, mental and emotional stress that can result from taking care of another person can lead to a huge health risk...namely, burnout! According to experts, there are three causes of caregiver burnout: caregiving duties, self-inflicted pressure and lack of proper rest. Pay attention to the following physical, mental and emotional warning signs:

Pay attention to these physical, mental and emotional warning signs of BURNOUT.

- Rapid change in weight or appetite
- Body aches and strains
- Migraines or persistent headaches
- Getting sick more often and for longer
- Exhaustion you can't shake, regardless of sleep
- Feeling distressed, frustrated, hopeless or alone
- Depression
- Anxiety and Panic Attacks
- Isolating yourself from others
- Low self-esteem

Caregiver burnout is very common. In the National Alliance for Caregiving and AARP Public Policy Institute survey, **40 percent** of caregivers felt emotionally stressed, almost **20 percent** said it caused financial problems, and about **20 percent** felt physically strained. It is estimated that **20 percent** of family caregivers suffer from depression, which is twice the rate of the general population.

Studies show that **30 to 40 percent** of dementia caregivers suffer from both **depression and emotional stress**, **16 percent** of dementia caregivers are emotionally strained, while **26 percent** state that taking care of their loved one who has dementia is hard on them emotionally.

What can be done to prevent burnout? The answer is...TAKE CARE OF YOU! There are five things you can do every day to ensure your role as a caregiver is both healthy for you and for the person you're caring for.



Get the right amount of rest and sleep each day to stay energized.



Eat 3 healthy meals each day.



Drink at least 8 glasses of water each day.



Exercise for at least 30 minutes each day.



Spend time with family and friends doing things that you enjoy, other than caregiving.

Upcoming Programs

“We Rise Together: Seniors Rebound with Resilience and Hope” featuring Boxing Legend, Ray “Boom Boom” Mancini

SAVE THE DATE

What: 2023 Phoebe Institute on Aging (PIA) Conference

When: Thursday, April 27, 2023

Where: DeSales University

Phoebe’s annual conference will examine resiliency in older adults, from normal aging processes to environmental stresses. Learn clinician and practitioner strategies and techniques to promote resiliency in seniors. Explore the support options available in the community to strengthen the resiliency of senior adults. Visit phoebe.org/pia-conference for more information.

Caregiver Support

Memory Cafe by Senior Solutions

[View PDF →](#)

Memory Support Groups

[View PDF →](#)

Memory Lane

[View PDF →](#)

EventFULL Living^{MSL}

[View PDF →](#)

AROUND-THE-CLOCK INFORMATION AND SUPPORT

**ALZHEIMER'S ASSOCIATION
24/7 HELPLINE: 800.272.3900**

The free Alzheimer's Association® 24/7 Helpline allows people living with Alzheimer's disease or dementia, caregivers, families and the public to:

- » Speak confidentially with master's-level care consultants for decision-making support, crisis assistance and education on issues families face every day.
- » Learn about the signs of Alzheimer's and other dementias.
- » Get general information about medications and other treatment options, and legal, financial and care decisions.
- » Find out about local programs and services.
- » Receive help in their preferred language through our bilingual staff or translation service, which accommodates more than 200 languages.
- » Access support through our TTY service (TTY: 866.403.3073) if assistance is required via a teletype device.

This project was supported, in part by grant number 90AC2811-01-00 from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects with government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official ACL policy.

alzheimer's  association®

800.272.3900 | alz.org®

alz.org/delval

Our Mission

The mission of DFLV is to raise awareness and reduce stigma related to Alzheimer's Disease and Related Disorders (ADRD) among community members and encourage the Lehigh Valley community to become more accessible and supportive for individuals affected by ADRD and their caregivers.



Be sure to go to www.dementialv.org to learn how you and your organization can be a part of making the Lehigh Valley a dementia-friendly community.

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