

# ADRC Moving Toward a Cure PATHWAYS

## Bridging a Gap in Dementia Research

By Sarah B. Berman, MD, PhD

The University of Pittsburgh Alzheimer Disease Research Center (ADRC) is proud to announce its participation in a nationwide effort to overcome a major gap in research to address one of the world's leading causes of dementia, dementia with Lewy bodies (DLB). Because I am the neurologist leading the ADRC in this effort, I prepared this question-and-answer overview of DLB and some information about an exciting new research study.

**What is DLB?** DLB, also termed Lewy body disease, is the second most

common degenerative dementia after Alzheimer's disease (AD). However, it often is underrecognized because its features overlap with other degenerative diseases, including AD and, more commonly, Parkinson's disease, making an accurate diagnosis complicated. Symptoms of DLB include changes in thinking that can include memory problems, but the memory difficulties experienced by people with DLB are usually less prominent than in those with AD, at least initially. Early on, people with DLB are more likely to have difficulties with interpreting visual information, paying attention, and organization. In addition, they often

experience fluctuations in alertness and thinking throughout the day, with times when they may seem to be zoning out or especially confused. Along with these cognitive changes, other symptoms of DLB include visual hallucinations, acting out dreams or talking in one's sleep, stiffness, tremors or shakiness, slowness, and shuffling one's feet when walking. DLB also can cause urination difficulties, constipation, light-headedness, loss of the ability to smell, and additional psychiatric symptoms. DLB typically develops after age 50 but can occur earlier.

*Continued on page 3*



# All of Us Pennsylvania

## Dear friends of the University of Pittsburgh Alzheimer Disease Research Center,

Thank you for your previous participation in Alzheimer's disease research studies. We want to let you know about another study that has the potential to have an impact on disease prevention and treatment: the All of Us Pennsylvania research program. This initiative is designed to advance precision medicine, which is health care that is based on each individual and takes into account factors like where you live, what you do, and your family health history. To make health care better in the future, we need to learn more about the differences that make each of us unique so that prevention and treatment can be more individually tailored.

All of Us Pennsylvania is part of the National Institutes of Health's All of Us Research Program, a 1 million-person study. The program involves completing some information online and then visiting one of the study's enrollment centers near you to provide physical measurements and give biosamples (blood and urine). You also will be asked to share your electronic health records.

Data that are collected will be broadly accessible to researchers of all kinds, including citizen scientists, to support thousands of studies across a wide range of different health topics. By sharing the data, we are hoping to discover how more precisely to prevent and treat health conditions. Knowledge gained from this research could help researchers to improve health for generations to come.

Everyone over the age of 18, regardless of gender, is eligible. You will receive compensation of \$25 after your visit.

You can be one in a million and help to change the future of medicine.

To join All of Us Pennsylvania, contact the call center at 412-383-2737. To learn more, visit [joinallofuspa.org](http://joinallofuspa.org).

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## Results of Research Study Show Statistically Significant Slowing of AD Progression

The Eisai Co., Ltd., and Biogen pharmaceutical companies have announced the results of a Phase II drug study (BAN2401) that demonstrated statistically significant slowing of Alzheimer's disease (AD) progression, as measured by cognitive tests, and reduction of amyloid beta accumulated in the brain, as measured by PET scans.

The study was conducted in 856 patients with early onset AD who were followed for a period of 18 months. The drug was well tolerated, and as expected, one of the most frequent side effects was the incidence of areas of inflammation in the brain detected by an MRI, but not more than 10 percent of study subjects who received the treatment were affected.

*These new data provide compelling evidence to further support the use of anti-amyloid agents in the treatment of AD.*

It is important to note that this is the first Phase II study in many years that has successfully demonstrated potential disease-modifying effects on both clinical function and amyloid beta accumulation in the brain. However, the final results will come from a large Phase III study that these companies will have to conduct to obtain regulatory approval to make the new drug available to the public.

These new data provide compelling evidence to further support the use of anti-amyloid agents in the treatment of AD.

"This study supports the amyloid hypothesis, and it shows us that these trials should be done with long observational periods. The drug showed little effect after a 12-month follow-up period, but it showed positive effects when the trial was extended to 18 months," says Oscar Lopez, MD, University of Pittsburgh Alzheimer Disease Research Center director.

# Bridging a Gap

Continued from page 1

**Why is it called DLB?** The name comes from the pathological changes in the brain that occur in DLB. A protein called alpha-synuclein accumulates abnormally inside brain cells. These cells become dysfunctional and can degenerate, eventually dying off. The abnormal protein accumulations are called Lewy bodies, named after the pathologist who first described them. Lewy body pathology can occur in multiple brain areas, including areas involved in cognition and in coordinating movement. Similar pathological changes are seen in Parkinson's disease but are more widespread in DLB.

*Those with DLB often react differently to medications than do those with AD or Parkinson's disease; thus, it is very important for people with DLB to receive individualized treatment for their symptoms.*

**How do we diagnose DLB?** DLB is best diagnosed with a thorough clinical history and neurological exam that includes cognitive testing. Doctors also might use additional testing, including laboratory testing, sleep studies, and specific imaging studies, to help in the diagnosis.

**How do we treat DLB?** We do not yet have medications that can reverse or prevent the progression of DLB, but appropriate treatment and management can significantly improve the quality of life. DLB, like other degenerative dementias, is a progressive disease, meaning that it worsens over time. However, there is significant variability in the clinical course from one person to the next. This variability is based on many factors, such as the degree of psychiatric symptoms or Parkinson's



disease-like changes in motor functioning. Those with DLB often react differently to medications than do those with AD or Parkinson's disease; thus, it is very important for people with DLB to receive individualized treatment for their symptoms. People with DLB can be extremely sensitive to medications used for hallucinations or delusions, for example, so it is important for the diagnosis to be recognized. Alternatively, some medications commonly used for AD can be beneficial when used for DLB, and initiating those therapies early may be helpful. Maintaining social and intellectual activities, regular physical exercise, and a healthy diet are important as well.

### **What DLB research is ongoing?**

Right now, there are no available treatments that can slow the progression of DLB, so we can treat only the symptoms. Therefore, it is critical to expand our research so that we can design specific therapies for DLB that slow the course of the disease. At the ADRC, we are excited to be part of a new national DLB Consortium study that is working to accelerate biomarker development and research to develop therapies to slow the disease's progression. The ADRC currently is

enrolling participants for this four-year study that will collect laboratory, clinical, and imaging data over time to accelerate the development of biomarkers and to better design and monitor clinical treatment testing.

**If you are interested in learning more about the DLB study and potentially participating in it, or if you have other questions about DLB, please contact Donna Simpson, clinical research coordinator, at 412-692-2717 or [simpsondm@upmc.edu](mailto:simpsondm@upmc.edu) for more information.**



Sarah B. Berman, MD, PhD

# Study to Reduce Agitation in AD Patients Is Now Recruiting Participants

Agitation is common in people who have Alzheimer's disease (AD) and can be a challenging behavior for the family and friends of these individuals. Agitation affects 42–60 percent of people with AD and involves emotional distress, excess psychomotor activity (moving around a lot), aggression, or disinhibition (saying or doing things that are out of character).

Treatment options for agitation in AD are limited. Current approaches are

inadequate, and better approaches are needed. **Escitalopram for Agitation in Alzheimer's Disease** (S-CitAD; see page 10 of this newsletter) is a placebo-controlled, randomized clinical trial sponsored by the National Institute on Aging and led by Johns Hopkins University. This study is designed to examine the efficacy and safety of escitalopram in combination with a psychosocial intervention as treatment

for agitation in AD patients. Individuals in the S-CitAD trial will be enrolled for 24 weeks, with treatment for 12 weeks and an additional 12 weeks of safety and efficacy follow-up, for a total of six clinic visits. For more information about this study at the Pittsburgh site, contact Patricia Henderson at 412-692-2703 or [hendersonpl@upmc.edu](mailto:hendersonpl@upmc.edu) or MaryAnn Oakley at 412-692-2721 or [oakleym@upmc.edu](mailto:oakleym@upmc.edu).



## Escitalopram for Agitation in Alzheimer's Disease Research Group (S-CitAD)

### Do You Care for Someone with Alzheimer's Disease Who is Suffering from Agitation?

#### Like memory loss, it is important to look for agitated behaviors in people with Alzheimer's disease.

Alzheimer's disease is typically associated with memory loss, but in more than half of people, it can also cause a condition called agitation. When a person develops agitation, his or her behavior can change in ways that seem out of character or extreme. Agitated behaviors can be nonaggressive or aggressive. The behavior may also be a sign that a person's Alzheimer's disease is getting worse.

It is important to look for signs of agitation in a person with Alzheimer's disease who is under your care and report behaviors to his/her health care provider.

Agitation can be defined as the presence of one or more of the following behaviors: excessive motor activity, verbal aggression, or physical aggression.



#### EXCESSIVE MOTOR ACTIVITY

- Pacing and aimless wandering
- Repetitive mannerisms (such as tapping, fidgeting, or picking at things)
- General restlessness
- Rocking
- Gesturing
- Pointing fingers

#### VERBAL AGGRESSION

- Cursing or verbal combativeness
- Shouting
- Speaking in an excessively loud voice
- Screaming (not related to pain)
- Yelling

#### PHYSICAL AGGRESSION

- Hitting or kicking
- Pushing or grabbing
- Biting or scratching
- Spitting (including when eating)
- Throwing things
- Hurting self or others
- Tearing things or destroying property
- Shoving
- Resisting
- Slamming doors

# 20 Things I Would Want If I Got Dementia

By Rachael Wonderlin, MS



**1.** If I get dementia, I want my friends and family to embrace my reality. If I think my spouse is still alive, or if I think we're visiting my parents for dinner, let me believe those things. I'll be much happier for it.

**2.** If I get dementia, don't argue with me about what is true for me versus what is true for you.

**3.** If I get dementia and I am not sure who you are, do not take it personally. My timeline is confusing to me.

**4.** If I get dementia, and can no longer use utensils, do not start feeding me. Instead, switch me to a finger-food diet and see if I can still feed myself.

**5.** If I get dementia, and I am sad or anxious, hold my hand and listen. Do not tell me that my feelings are unfounded.

**6.** If I get dementia, I don't want to be treated like a child. Talk to me like the adult that I am.

**7.** If I get dementia, I still want to enjoy the things that I've always enjoyed. Help me find a way to exercise, read, and visit with friends.

**8.** If I get dementia, ask me to tell you a story from my past.

**9.** If I get dementia, and I become agitated, take the time to figure out what is bothering me.

**10.** If I get dementia, treat me the way that you would want to be treated.

**11.** If I get dementia, make sure that there are plenty of snacks for me in the house. Even now if I don't eat I get angry, and if I have dementia, I may have trouble explaining what I need.

**12.** If I get dementia, don't talk about me as if I'm not in the room.

**13.** If I get dementia, don't feel guilty if you cannot care for me 24 hours a day, 7 days a week. It's not your fault, and you've done your best. Find someone who can help you, or choose a great new place for me to live.

**14.** If I get dementia, and I live in a dementia care community, please visit me often.

**15.** If I get dementia, don't act frustrated if I mix up names, events, or places. Take a deep breath. It's not my fault.

**16.** If I get dementia, make sure I always have my favorite music playing within earshot.

**17.** If I get dementia, and I like to pick up items and carry them around, help me return those items to their original places.

**18.** If I get dementia, don't exclude me from parties and family gatherings.

**19.** If I get dementia, know that I still like receiving hugs or handshakes.

**20.** If I get dementia, remember that I am still the person you know and love.

**Rachael Wonderlin** is a dementia care consultant and author of *When Someone You Know Is Living in a Dementia Care Community: Words to Say and Things to Do*. She also hosts a blog at [dementia-by-day.com](http://dementia-by-day.com). You can contact Wonderlin at [rachaelwonderlin.com](http://rachaelwonderlin.com).

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Visit Our  
Web Site**

For up-to-date information about the Alzheimer Disease Research Center, the Brain Donation Program, clinical trials, and community presentations, please visit [www.adrc.pitt.edu](http://www.adrc.pitt.edu).

# Making Yourself a Priority: Tips for Caregivers' Self-Care

By Sarah T. Stahl, PhD

Taking care of yourself is one of the most important things you can do as a caregiver. We know that eating a balanced diet, exercising, and staying socially engaged are all important components of a healthy lifestyle. Many times, though, caregivers can forget to take care of themselves simply because they are feeling stressed or overwhelmed with their caregiving responsibilities.

The demands of caregiving can harm even the most resilient person. You may be so focused on taking care of your loved one that you don't realize that it is taking a toll on your own health. Some signs of caregiver stress include not getting enough sleep, gaining or losing weight, losing interest in activities you used to enjoy, and having frequent headaches or other physical problems. Taking care of yourself could bring you some relief, reduce your stress, and make you more capable—physically and emotionally—of caring for your loved one. Spending some time on yourself could also keep you from getting sick or feeling depressed.

Here are some things you can do to make yourself a priority:

- **Find ways to exercise.** Go for a walk, garden, or do yoga. Try exercising with the person you are caring for—they might need it, too!
- **Get some sleep.** Go to bed and get up at about the same time every day. If you are up at night caring for your loved one, try taking a power nap (15–30 minutes) during the day between 1 and 3 p.m., when your body naturally wants to rest.
- **Eat healthy foods.** Keep it simple: Eat more foods that are fresh and colorful and fewer foods that are processed or come in a package.
- **Socialize and spend time with others.** Set aside time each week to connect with family or friends. If you don't have the freedom to get out and socialize, try e-mailing, using Facebook, or talking on the phone.
- **Keep up with your hobbies and interests.** Try spending a few minutes a day doing what you love.

It can help to restore your sense of self and confidence.

- **Join a caregiver support group, either online or in person.** Connecting with other caregivers will allow you to share your experiences and learn strategies for dealing with difficult situations. It also can be a good place to develop meaningful relationships. Ask about caregiving services such as transportation, meal delivery, or housekeeping that might be available.
- **See your doctor.** Maintain regular doctor visits. Get regular health screenings and vaccinations. Tell your doctor that you are a caregiver. Bring a list of questions and take notes on what your doctor recommends.
- **Get help from a counselor if caregiving becomes too much.** If you are feeling sad, down, or depressed, a mental health professional can help you to deal with it.
- **Ask for help when you need it.** Take advantage of whatever help is available to you. Make a list of ways that family and friends can help you. Consider respite care services such as health care aids, adult care centers, and short-term nursing homes. Contact your local Area Agency on Aging to learn about services in your community.

With these tips in mind, researchers at the University of Pittsburgh developed a tool to help people track their health while providing care for a loved one. But we need help from you! We want to know what kind of health information is important to caregivers. If you would like to share your input, please contact me at 412-246-6003 or sarah.stahl@pitt.edu. I would be happy to talk with you about a study to utilize this tool. With your help, the Pitt Alzheimer Disease Research Center can better understand how to promote the health and well-being of caregivers.



# Outreach Happenings

By Melita Terry, BS, Outreach Coordinator



What's the buzz all about? The University of Pittsburgh Alzheimer Disease Research Center (ADRC) is continuing to make inroads in underrepresented communities throughout Pittsburgh and surrounding areas, heightening awareness of brain health and Alzheimer's disease (AD).

From January through May of this year, the ADRC participated in several health fairs, YMCA events, church- and library-sponsored activities, senior days, and other gatherings in local communities to help educate the senior population about normal aging.

The ADRC is pleased to continue its relationship with the Urban League of Greater Pittsburgh in efforts to recruit African American participants

for AD research. Ann D. Cohen, PhD, assistant professor of psychiatry at the University of Pittsburgh, and I spoke about AD at the Urban League Lunch and Learn in February. You can watch the presentations on YouTube at <https://www.youtube.com/watch?v=tQ-ONhRab0w>. In addition to this effort, the ADRC hosted a Coffee and Conversation event with Keisha Ward, MD, at Crazy Mocha Coffee Company in Pittsburgh's Hill District on February 28.

The most recent Walter Allen Memorial Community Lecture took place in May at the Hill House Association. Guest speaker Rachael Wonderlin, who has a Master of Science degree in gerontology, gave a lighthearted presentation on communicating with people who have AD and other forms of dementia.

On Saturday, July 14, the stage play *Forget Me Not* by Garrett Davis was performed at the August Wilson Center in downtown Pittsburgh. The showing was made possible by the ADRC and a number of community sponsors. *Forget Me Not* was designed to raise awareness of AD within ethnically diverse urban communities. It highlights the importance of knowing the signs of AD and understanding its impact on the caregiver, family, and community. More than 350 community members attended the play.

If you would like your organization (e.g., a book club, church, or other group) to get involved in AD education and research, please contact me at 412-692-2712 or [terrymh@upmc.edu](mailto:terrymh@upmc.edu).

# Of Note

**Beth Sarles-Shaaban** received her PhD in epidemiology from the University of Pittsburgh on April 29, 2018. Sarles-Shaaban was the ADRC neuropsychology program coordinator from 2002 to 2013. She will be starting a postdoctoral associate position in September working on population neuroscience and the vascular biology of aging and Alzheimer's disease in the Department of Epidemiology at Pitt's Graduate School of Public Health. Congratulations, Dr. Sarles-Shaaban!



Beth Sarles-Shaaban, PhD

## Lopez Presents Inaugural Lecture as Endowed Chair

Provost and Senior Vice Chancellor Patricia E. Beeson is pleased to continue the tradition of inviting distinguished faculty members to present an inaugural lecture to celebrate their appointments to endowed chairs.



Oscar Lopez, MD

The 2018 Provost's Inaugural Lectures began on February 13, with ADRC Director Oscar Lopez, MD, presenting "Vascular Factors and Alzheimer's Disease: Independent

Amyloid and Vascular Components Conspire to Cause Alzheimer's Disease" to celebrate his appointment to the Levidow-Pittsburgh Foundation Chair in Alzheimer's Disease and Dementia Disorders.

# With Gratitude

The University of Pittsburgh Alzheimer Disease Research Center thanks the following individuals and organizations for their generous donations received between January 5 and June 1, 2018.

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You now can donate to the ADRC online  
at [giveto.pitt.edu/adrc](http://giveto.pitt.edu/adrc).

## Thank you!

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Please make your check payable to the Alzheimer Disease Research Center and send your contribution to the following address:

University of Pittsburgh  
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# Research Studies

## Volunteer!

Get involved! We are in constant need of participants for several research studies and invite anyone with interest to call the University of Pittsburgh Alzheimer Disease Research Center at 412-692-2721 or e-mail [oakleym@upmc.edu](mailto:oakleym@upmc.edu).

### Alzheimer's Disease Neuroimaging Initiative 3 (ADNI3) Study

**Description:** The overall goal is to determine the relationships among the clinical, cognitive, imaging, genetic, and biochemical biomarker characteristics of the entire spectrum of Alzheimer's disease (AD) from its earliest stages. Subjects will undergo longitudinal clinical and cognitive assessments, computerized cognitive batteries, biomarker and genetic tests, PET (FDG, amyloid, and tau) and MRI scans, and cerebral spinal fluid collection.

**Study Length:** Up to five years

#### Study Requirements:

- 55–90 years of age
- Normal cognition or a diagnosis of mild cognitive impairment or AD
- A study partner who will accompany you to all study visits

**Contact:** MaryAnn Oakley at 412-692-2721 or [oakleym@upmc.edu](mailto:oakleym@upmc.edu)

### Dementia with Lewy Bodies Consortium Study

**Description:** The purpose of this study is to collect clinical information, brain imaging scans, and biological samples from people who have dementia with Lewy bodies (DLB). This information will help researchers to improve the diagnosis, care, and treatment of patients with this disease.

**Study Length:** Five years

#### Study Requirements:

- 40–90 years of age
- Diagnosis of DLB or high likelihood
- A study partner who will accompany you to all study visits

**Contact:** Donna Simpson at 412-692-2717 or [simpsondm@upmc.edu](mailto:simpsondm@upmc.edu) or MaryAnn Oakley at 412-692-2721 or [oakleym@upmc.edu](mailto:oakleym@upmc.edu)

### Escitalopram for Agitation in Alzheimer's Disease (S-CitAD)

**Description:** This study is designed to examine the efficacy and safety of escitalopram in combination with a psychosocial intervention as treatment for agitation in Alzheimer's disease (AD) patients.

**Study Length:** Six months

#### Study Requirements:

- Diagnosis of AD with significant agitation/aggression
- A study partner who will accompany you to all study visits

**Contact:** Patricia Henderson at 412-692-2703 or [hendersonpl@upmc.edu](mailto:hendersonpl@upmc.edu) or MaryAnn Oakley at 412-692-2721 or [oakleym@upmc.edu](mailto:oakleym@upmc.edu)

### Lithium as a Treatment to Prevent Impairment of Cognition in Elders (LATTICE)

**Description:** The purpose of this study is to examine the potential disease-modifying properties of lithium in individuals with mild cognitive impairment (MCI).

**Study Length:** Two years

#### Study Requirements:

- 60 years of age or older
- Diagnosis of MCI

**Contact:** MaryAnn Oakley at 412-692-2721 or [oakleym@upmc.edu](mailto:oakleym@upmc.edu)

## Sleep Study (Prefrontal Cortex Stimulation in MCI)

**Description:** Previous research has shown that certain forms of brain stimulation can affect sleep patterns as well as cognitive function. The goal of this study is to test whether changes in sleep patterns with brain stimulation influence cognition in people with mild cognitive impairment (MCI).

**Study Length:** 14 days

**Study Requirements:**

- Diagnosis of MCI
- 60–85 years of age
- Normal or corrected-to-normal visual and auditory acuity

**Contact:** MaryAnn Oakley at 412-692-2721 or oakleym@upmc.edu

## Connectomes in Brain Aging Study

**Description:** This study will determine how different parts of the brain are connected and how these connections allow people to think, behave, and feel. The study will involve two to three days of scanning and tests. Some people will be asked to return after two years.

**Study Length:** Two to three days for all participants; two years for some participants

**Study Requirements:**

- 50–89 years of age
- Normal cognition or a diagnosis of mild cognitive impairment or AD

**Contact:** Rebecca Roush at 412-586-9860 or roushre2@upmc.edu or MaryAnn Oakley at 412-692-2721 or oakleym@upmc.edu

## Ask the Medical Professional

- Q.** Our doctor says that my husband has dementia. What is the difference between dementia and Alzheimer's disease?
- A.** Dementia is the loss of intellectual functioning—thinking, remembering, and reasoning—to such an extent that it interferes with a person's daily life and activities. Dementia is an umbrella term that embraces a number of conditions. Alzheimer's disease (AD) is one kind of dementia that is caused by physical, nonreversible changes in the brain. There are many other kinds of dementia besides AD. Lewy body disease, Pick's disease or frontotemporal dementia, and vascular dementia (related to small strokes or transient ischemic attacks) are other types of dementia. Pseudo dementias can occur when other conditions (depression, thyroid disease, malnutrition, infections, or the use of certain medications) are present and similar symptoms are exhibited. These pseudo dementias often are treatable, and when such symptoms occur, a thorough medical evaluation is always a good first step to take.



## TEAM BUILDING



ADRC staff members enjoy an evening at the bowling alley.

## The Alzheimer's Association 24-hour help line

provides reliable information and support to all who need it.

Call the toll-free hotline anytime, day or night, at **1-800-272-3900.**





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