

2017 Alzheimer's Disease & Related Disorders Forum:



HELP PENNSYLVANIA FIGHT ALZHEIMER'S

On Wednesday, April 12, the Pennsylvania Department of Aging held a 2017 Alzheimer's Disease and Related Disorders (ADRD) Regional Forum at the Ralston House in Philadelphia.

"The challenges for individuals living with Alzheimer's disease or a related disorder, and those who selflessly care for them, are often staggering," said **Teresa Osborne**, Pennsylvania Secretary of Aging, during the roundtable discussion. "In Pennsylvania, over 400,000 individuals are afflicted with Alzheimer's disease or a related disorder, and that number is expected to increase markedly as the baby boomer generation reaches the age of 65 and beyond."

The forum brought together stakeholders from local communities throughout the Philadelphia area and the surrounding counties to discuss their engagement in, and the progress of, Pennsylvania's State Plan for Alzheimer's Disease and Related Disorders. It also provided the opportunities to discuss the many different experiences and responses to dementia in and around Philadelphia and to help promote and support the development of a community action plan.

This was the seventh and final forum in the series of regional meetings held throughout the commonwealth aimed at engaging community leaders and fostering a deeper understanding of Alzheimer's and the public health crisis it poses.

Read more at: www.pennmemorycenter.org

For more information on the PA State Plan for ADRD, visit: www.aging.pa.gov

UPCOMING EVENTS

SYLVAN M. COHEN ANNUAL RETREAT & Poster Session

Genetics of Aging-related Neurodegeneration
Tuesday, May 23, 2017 | 11:30 - 5:00 PM
Smilow Center for Translational Research
University of Pennsylvania

Co-hosts:

Penn Neurodegeneration Genomics Center (PNGC)

Keynote Speaker:

Philip De Jager, MD, PhD
Harvard Medical School

Penn Presenters:

Gerard D. Schellenberg, PhD,
Adam Naj, PhD,
& Nancy Zhang, PhD

Poster Session:

Immediately following the retreat's lectures, we will host our annual poster session. All aging-related topics are welcome!

Poster Categories:

Basic Science,
Clinical Research,
or Education & Community

Prizes will be awarded to the top posters in each category.

This event is free and open to the public, but **registration is required.**

Learn more, submit a poster, & register online:
www.med.upenn.edu/aging



FORGETFULNESS:

Normal or Not?

Many people can become more forgetful as they age.

How can you tell the difference between

mild forgetfulness & **serious memory problems**

like Alzheimer's disease?

See what's typical and what's not:

NORMAL AGING

- Making a bad decision once in a while
- Missing a monthly payment
- Forgetting which day it is and remembering later
- Sometimes forgetting which word to use
- Losing things from time to time

ALZHEIMER'S DISEASE

- Making poor judgments and decisions a lot of the time
- Problems taking care of monthly bills
- Losing track of the date or time of year
- Trouble having a conversation
- Misplacing things often and being unable to find them



Although some forgetfulness comes with age, don't ignore changes in memory or thinking that concern you.

Talk with your doctor if you notice you have more serious memory problems than normal.



Visit www.nia.nih.gov/understanding-memory-loss for more information about forgetfulness and memory loss.



THE ASSUMPTIONS OF AGING:

Addressing the Myths & Stereotypes of Getting Older

On Thursday, April 13, 2017, the Philadelphia Corporation for Aging (PCA) held a daylong training course titled "Assumptions of Aging," led by **Kathy Jedrzewski, PhD**, Deputy Director of the Institute on Aging (IOA) at the University of Pennsylvania.

The purpose of this training was to address and debunk some of the common myths and stereotypes that are often associated with the aging population. Participants in the course ranged from social work coordinators and senior counselors to service coordinators from PCA and other local senior service centers. While this goes for the general public as well, it is especially important for individuals in these lines of work to understand and differentiate between the truths of aging and the negative labels that often overshadow in the elderly community so that they can provide the level of service — and respect — that seniors need and deserve.

Debunking Some of the Myths:

1. Older people are not good with technology:

One of the most common misconceptions about the aging community is that they do not know — or cannot learn — how to use technology. While it may take some older individuals longer to pick up on the latest devices, they are not incompetent. Many older adults actually enjoy learning the current technology and internet trends as it provides a way to stay engaged and in touch with the ever-evolving means for communicating and consuming information (i.e. social media). In fact, according to *Pew Research Center*, 56% of U.S. online users ages 65 and up use Facebook.

2. Older people cannot maintain the same hobbies, activities, or social life that they had when they were younger

As people age, they often feel pressure from their peers, relatives, and even from themselves to re-evaluate and restrict their idea of what is "appropriate" for them. Whether it is a choice in clothing, a physical hobby such as sports or exercise, or even something as personal as dating or physical intimacy, older adults often think or hear that they are "too old for that." However, if an individual is still physically and mentally capable, their age alone should never determine what they can or cannot do.

3. Older people with disabilities are helpless and useless

One of the most important things to understand about an individual with a disability is that it does not define them as a person. It is a common myth that individuals, particularly seniors, with disabilities need to be catered to and treated as children. In reality, this can actually have a negative effect, stripping them entirely of their sense of independence, and in some cases, their self-worth. It is important for family members, caregivers, and others to understand that as long as the individual is still cognitively and/or physically capable of doing something — whether it is making their own decisions or taking part in normal day-to-day activities — they should be given the opportunity and respect to do so.

4. Memory loss is a normal part of aging

Although occasional forgetfulness can be perfectly normal as we age, frequent and more severe memory problems are not. The National Institute on Aging (NIA)'s infographic (pictured left) describes some of the basic differences between normal and unusual forgetfulness, but if you or someone close to you starts to notice a sudden or recurrent change in your cognition, it is important to talk with your doctor to understand what is causing your symptoms and to rule out the possibility of a more serious medical problem.

"I love doing this training at PCA twice a year," said Dr. Jedrzewski, leader of the training session. "It gives me a chance to meet staff from across the aging network who are doing such important work, impacting lives every day and hopefully I give them some tools to work with."

PCA is a private nonprofit organization serving the Philadelphia area with a broad range of services to help older Philadelphians live as independently as possible. In addition to providing training programs to individuals working in aging-related fields, they also offer services such as advocacy programs, coordinating in-home care, legal assistance, and home-delivered meals. It is the largest of 52 Area Agencies on Aging in Pennsylvania and assists more than 134,000 individuals through its PCA Helpline each year.

Read more: www.penninstituteonaging.wordpress.com

LYTICO-BODIG: Could this rare neurodegenerative disease once widespread in Guam be the key to unlocking answers in Alzheimer's and related diseases?

From Penn Medicine Magazine Winter 2017's 'Guam's "Skeleton Key" Enigma'

For decades, lytico-bodig, a rare neurodegenerative disease once widespread in Guam, sent researchers on a hunt for answers – including some that may unravel desperately-needed information about Alzheimer's and other neurodegenerative diseases.



The first official reports of lytico-bodig appearing in Guam were in 1904. By the 1950's it was a full-scale epidemic afflicting the people of this small South Pacific island with a population of a little under 60,000 at a rate 100 times greater than similar neurodegenerative diseases did and quickly became the leading cause of death among the locals. Researchers hoped that this disease, sharing many of the same characteristics of Parkinson's, Alzheimer's and Amyotrophic lateral sclerosis (ALS or Lou Gehrig's disease), could be the key to some of their looming questions, however, they found only "decades of dead ends," said Gerard (Jerry) D. Schellenberg, PhD, professor of Pathology and Laboratory Medicine at the University of Pennsylvania in the Winter 2017 Penn Medicine Magazine. "If we could solve Guam's disease at some point, it would help with these other neurodegenerative disorders. Or, it may be the other way around."

In the 1990's, John Q. Trojanowski, MD, PhD, director of Penn's Institute on Aging, Alzheimer's Disease Core Center, and Udall Center for Parkinson's Research, and Virginia M.-Y. Lee, PhD, Director of Penn's Center for Neurodegenerative Disease Research, joined in the research efforts on lytico-bodig. They found that lytico-bodig and Alzheimer's disease resembled each other not only symptomatically, but they also shared molecular similarities.

Drs. Trojanowski and Lee believed that tau tangles, the hallmarks of Alzheimer's disease and an underlying feature in lytico-bodig, could reveal

clues to its cause. According to Guam's "Skeleton Key" Enigma, while tau tangles in lytico-bodig are more prominent in the spinal cord compared to other diseases, the brain of a lytico-bodig patient is actually very comparable to the brain of an Alzheimer's patient. In later studies, Drs. Trojanowski and Lee showed that many of the misfolded proteins in other neurodegenerative diseases, such as amyloid plaques, alpha-synuclein, and TDP-43, were also present in some lytico-bodig patients.

Dr. Schellenberg – who collaborates closely with Drs. Trojanowski and Lee in a variety of research efforts -- was focusing on a separate project looking at genetics and environmental exposure. According to the article, he and his research team found microtubule-associated tau proteins contributed to a higher risk of developing lytico-bodig, but that something else, such as an environmental factor, would be needed to officially trigger the disease.

"The problem is that when you say environmental risk factor, the first thing that comes to mind is that people are eating a toxin," explained Dr. Schellenberg. However, "it could also mean that you are consuming something protective – a diet [that] perhaps protects you against the lytico-bodig in Guam. You may be looking for something rare that disappeared, or something that has now become more common that protects."

Today, after decades of "dead ends," the hunt for answers has seemingly come to a halt. "Guam contributed to new ideas for therapies to treat Alzheimer's, but I don't see a path forward for lytico-bodig," said Dr. Trojanowski – at least for now. Dr. Schellenberg holds a bit more hope. "I have samples, all sorts of information. If something new comes up, I'll find a way to pursue it," he said.

To read the full article on Guam's "Skeleton Key" Enigma, visit:
www.pennmedicine.org/news/publications-and-special-projects



Fiscal Year 2018 **PILOT AWARDS**

INSTITUTE ON AGING

Biomarkers for misfolded a-syn fibril strains in Parkinson disease

PI: Rizwan S. Aktar, MD, PhD

Elucidation of Cell-type Specific Transcriptomic Profiles in Neurodegenerative Brain

PI: Mingyao Li, PhD

Endotypical Correlations of Speech Patterns in Frontotemporal Degeneration

PI: Mark Liberman, PhD

Characterization of Alzheimer's disease-linked MHC Polymorphisms within the HLA-DRB Locus

PI: Dimitri Monos, PhD & Brad Johnson, MD, PhD

ALZHEIMER'S DISEASE CENTER

Palliative Care Consultations for Persons with Advanced Dementia in the Medicare Skilled Nursing Setting

PI: Mary Ersek, PhD

Effects of episodic memory on economic decision-making in older adults with and without biological markers of preclinical Alzheimer's Disease

PI: Joseph Kable, PhD

To learn more about the 2018 Institute on Aging and Alzheimer's Disease Center Pilots, including full abstracts, visit:

www.med.upenn.edu/aging/PilotAwards.html

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The mission of the Institute on Aging at the University of Pennsylvania is to improve the health of older adults by increasing the quality and quantity of clinical and basic research as well as educational programs focusing on normal aging and aging-related diseases across the entire Penn campus.



SAVE THE DATE

 Penn Medicine

PENN'S 5K FOR THE IOA

The Institute on Aging

& THE MEMORY MILE WALK

Sunday, September 24th, 2017 8:00 am @ Penn Park