

**iADC**

Indiana Alzheimer Disease Center

# Reflections



Spring  
2016

INDIANA ALZHEIMER DISEASE CENTER NEWSLETTER  
INDIANA UNIVERSITY SCHOOL OF MEDICINE

2016  
Volume 25  
Issue 3

## IADC Welcomes Dr. Bruce Lamb, new director of the Stark Neurosciences Research Institute at IUSM



**Bruce T. Lamb, PhD**

Dr. Bruce Lamb (PhD, Molecular Biology, University of Pennsylvania, Philadelphia, PA (1991); Post-Doc, Cellular/Molecular Biology, Johns Hopkins University, Baltimore, MD (1994)) comes to Indiana University School of Medicine (IUSM) from the Lerner Research Institute at the Cleveland Clinic. Dr. Lamb's research has focused on the basic disease mechanisms of Alzheimer's Disease (AD) including the genetic factors involved in the metabolism and buildup of the protein that makes up the plaque deposits associated with the disease. His work has shed light on how complex mechanisms associated with AD have hampered efforts to find effective treatments in clinical trials. His lab also has studied the relationship between traumatic brain injury and AD.

Dr. Lamb has received numerous awards and honors including the Jennifer B. Langston Award from the Cleveland Chapter of the Alzheimer's Association and the National Civic Award and Zaven Khachaturian Lifetime Achievement Award from the National Alzheimer's Association. He is a Fellow in the American Association for the Advancement of Science and a member of the Medical and Scientific Advisory Council of the National Alzheimer's Association.

Dr. Lamb, on joining the Stark Neurosciences Research Institute on January 18, 2016, became the first holder of the Roberts Family Chair in Alzheimer's Disease Research. Motivated to help eradicate AD, David and Susan Roberts established The Roberts Family Chair in Alzheimer's Disease Research to honor David's father Wayne Roberts, who died from the disease.

Dr. Lamb succeeds Gerry Oxford, PhD, founding director of the Stark Neurosciences Research Institute, who is retiring. The Stark Institute was developed in 2003 as a multidisciplinary research institute in the neurosciences with the assistance of a gift from Paul and Carole Stark. Approximately 50 IU scientists are primary investigators and members of the Stark Institute, conducting research in such areas as pain, spinal cord and brain injury, addiction, movement and neurodegenerative disorders.

The Indiana Alzheimer Disease Center (IADC) is excited to have Dr. Lamb join the team where he is a member of the IADC Executive Committee. Dr. Lamb looks forward to enhancing and expanding the AD research program at IU, including basic science, translational and clinical research efforts. Indeed, with the recent substantial increases in AD research funding by the federal government, there are unique opportunities to promote and expand AD research at IU. Dr. Lamb looks forward to being part of these critical efforts to help accelerate the research programs that will ultimately lead to effective therapies and treatments for patients and their families. We look forward to many productive collaborations.

# Dr. Ghetti receives the Alzheimer’s Association of Greater Cincinnati Chapter’s Highest Honor

## Inside this issue:

2	Dr. Ghetti Honored
3	Guest Speakers visit IADC
4	Researchers link changes due to medications
5	Home Care Affordable
6	Brain Health
7-11	Current Studies
12	Study Information for Amyloid PET imaging
13	IDEAS Study
14	Memory University 2016
15	Save the Date(s) 25th Celebration
16	For the Caregiver... Communication Strategies
17	For the Caregiver... Incontinence
18	Resources and Links
19	Generous Gifts
20	More Research News and Get Connected
21	IADC Out and About
22	Faculty and Staff News
23	Get Dancing!

The Alzheimer’s Association of Greater Cincinnati recently recognized Dr. Bernardino Ghetti, founding director of the Indiana Alzheimer Disease Center (IADC) and Leader of the Neuropathology Core with their President’s Award. Ms. Paula Kollstedt, Executive Director of the Chapter, explained that the President’s Award is reserved for those rare individuals whose incredible professional achievements and personal dedication to the care and cure of those facing Alzheimer’s disease and related dementias, are making a truly significant contribution to our community – and to our world.

Dr. Bernardino Ghetti – Distinguished Professor, Indiana University; and Chancellor's Professor, Indiana University, Purdue University Indianapolis Indiana University School of Medicine, Department of Pathology and Laboratory Medicine – personifies those qualities. His groundbreaking investigations of neurodegenerative diseases, and outstanding contributions to science, including frontotemporal degeneration and Alzheimer’s disease among others, have advanced the understanding of those devastating illnesses.

In her speech, Ms. Kollstedt remarked that *not only is Dr. Ghetti an acclaimed researcher and physician, he is also an extraordinary human being. He has helped those we serve in our chapter in very profound ways – many times when they are at their most vulnerable – and has advanced public understanding of dementia in a truly unique way. Not once did Dr. Ghetti ever say “no” to a request from one of our staff or our constituents. For more than a decade he has been an enormously popular guest speaker, counselor and confidant to all of us. It is truly difficult to put into words how much he has contributed to so many.*

The IADC congratulates Dr. Ghetti on receiving the 2015 President’s Award from the Alzheimer’s Association of Greater Cincinnati. We are very proud of his accomplishments.



**Bernardino Ghetti, MD**

# Special Guest Lecturers

William T. Hu, MD, PhD



Andrew Saykin, PsyD introduced Dr. Hu, MD, PhD

William T. Hu, MD, PhD, Assistant Professor of Neurology, Emory University School of Medicine's Center for Neurodegenerative Diseases was guest lecturer over the lunch hour in February 2016. Dr. Hu presented "These Go To Eleven: Biomarkers, diagnosis, and the biology of Alzheimer's disease and related disorders".



Dr. Hu answers questions.

Maria Grazia Spillantini, PhD



Maria Grazia Spillantini, PhD

"Untangling Protein Aggregation in Neurodegenerative Diseases" was presented by guest lecturer Maria Grazia Spillantini, PhD, Professor of Molecular Neurology, University of Cambridge, UK in March 2016. Dr. Spillantini was the guest of Dr. Bernardino Ghetti, the Indiana Alzheimer Disease Center and the Stark Neurosciences Research Institute.



Bernardino Ghetti, MD and Maria Grazia Spillantini, PhD

# IADC Researchers reported links in physical changes seen on brain scans to cognitive risks of widely used medications.

A research team led by Shannon Risacher, PhD, Assistant Professor of Radiology and Imaging Sciences, has suggested that older adults might want to avoid using a class of drugs that are commonly used in over-the-counter products such as nighttime cold medicines because of their links to cognitive impairment.

Our researchers found lower metabolism and reduced brain sizes among study participants taking the drugs known to have an anticholinergic effect, meaning they block acetylcholine, a nervous system neurotransmitter, and this is known to lead to cognitive impairment. The study, "[Association Between Anticholinergic Medication Use and Cognition, Brain Metabolism, and Brain Atrophy in Cognitively Normal Older Adults](#)," was published online in the journal *JAMA Neurology*.

"These findings provide us with a much better understanding of how this class of drugs may act on the brain in ways that might raise the risk of cognitive impairment and dementia," said Dr. Risacher, Ph.D. "Given all the research evidence, physicians might want to consider alternatives to anticholinergic medications if available when working with their older patients," Dr. Risacher advises.

Drugs with anticholinergic effects are sold over the counter and by prescription as sleep aids and for many chronic diseases including hypertension, cardiovascular disease, depression and chronic obstructive pulmonary disease.

[A list of anticholinergic drugs and their potential impact is here.](#)

Previous research found a link between the anticholinergic drugs and cognitive impairment and an increased risk of dementia. This new paper is believed to be the first to study the potential underlying biology of those clinical links using

neuroimaging measurements of brain metabolism and atrophy. A 2013 study by our colleagues at the IU Center for Aging Research and the Regenstrief Institute found that drugs with a strong anticholinergic effect cause cognitive problems when taken continuously for as few as 60 days. Drugs with a weaker effect could cause impairment within 90 days.

The current research project involved 451 participants, 60 of whom were taking at least one medication with medium or high anticholinergic activity. The participants were drawn from the Indiana Memory and Aging Study and from the Alzheimer's Disease Neuroimaging Initiative, for which Andrew Saykin, Psy.D., is director of the Genetics Core and the Director of the Indiana Alzheimer Disease Center.

In the current study the researchers replicated the earlier findings of cognitive effects, and identified metabolism differences using positron emission tests (PET) and brain structure differences using magnetic resonance imaging (MRI) scans.

Dr. Risacher's work has received much attention in the press both locally ([WFYI](#)), nationally ([CNN](#), [Time](#) and ABC World News Tonight), and internationally (CBC).

**Risacher SL**, McDonald BC, Tallman EF, West JD, Farlow MR, Unverzagt FW, Gao S, Boustani M, Crane PK, Petersen RC, Jack CR Jr, Jagust WJ, Aisen PS, Weiner MW, Saykin AJ; Alzheimer's Disease Neuroimaging Initiative. Association Between Anticholinergic Medication Use and Cognition, Brain Metabolism, and Brain Atrophy in Cognitively Normal Older Adults. *JAMA Neurology*, 2016 Apr 18.

## New low-cost workforce extends primary care to homes of older adults

INDIANAPOLIS -- A new study from the Indiana University School of Medicine and the Regenstrief Institute has found that person-centered dementia care, which involves both patients and their caregivers, can be effectively provided by an engaged low-cost workforce -- care coordinator assistants.

Under the close supervision of clinical professionals, the care coordinator assistants, known as CCAs, work as integral health care team members conducting home and phone visits with dementia patients and family caregivers. CCAs, who typically have at most two years of post-high school education, are selected through a rigorous and innovative screening process. Once hired and trained, CCAs are assigned tasks focused on patient engagement and caregiver support that require less training and expertise than that of nurses or social workers.

As the number of older adults increases and health care resources cannot keep pace, the question of how to provide good care for this growing population has become increasingly pressing.

"We have shown that with good management, supervision, and support, CCAs can be effective primary care extenders enabling many tasks important to providing best practice care for older adults to be "shifted" down," said social psychologist and Alzheimer's disease educator Mary Guerriero Austrom, Ph.D., who led the study. "The key is screening to select the right people -- people who are comfortable with older adults with cognitive issues -- and then teaching and training them [CCAs], and giving them the resources and support they need to do the job. If you take care of your people, they will do an excellent job of taking care of patients."

CCAs are the health care team's eyes and ears in the community and the homes where patients and their caregivers live.

"If something happens -- the CCAs handle it or, when appropriate, bring it to the team's attention," said Dr. Austrom, the Wesley P. Martin Professor of Alzheimer's Education at the IU School of Medicine. "This is a bare-bones model that others can adopt and replicate. Care of older adults cannot be restricted to the clinic or physician's office. CCAs, the least expensive member of the health care team, can extend best-practice care in a cost effective manner."

During the period of the study, CCAs working for Eskenazi Health's Aging Brain Care (ABC) Medical Home mobile memory care clinic were divided into teams under the shared supervision of nurses and social workers with whom the CCAs met regularly. Some CCAs were staff of CICOA, the local Area Agency on Aging. These CCAs provided expertise to others on accessing Meals on Wheels, identifying transportation options, procuring durable medical equipment and other services of critical importance to the population they serve. Over 1,200 patients received an average of about 16 home and phone CCA visits during a one-year period.

In addition to extending the reach of the clinic, task shifting to CCAs provided the medical team with a population health overview of all of the older adults with dementia and their caregivers in the study. The electronic tracking system in place at the ABC Medical Home supplied information on an individual patient who did not appear to be stable or a caregiver who was experiencing stress or depression. This allowed the medical team to provide timely patient/caregiver-centered care as well as giving the team a better perspective of what was working well across the entire population and what was not.

"Workforce Development to Provide Person-centered Care" has been published online ahead of print in the journal of the peer-reviewed journal *Aging & Mental Health*. The paper describes the development of an extremely competent workforce committed to person-centered care for patients with dementia or depression and their caregivers. The authors discuss the importance of providing person-centered care, the significance of support by hospital leadership as well as staff support and professional development of CCAs.

"CCAs are problem solvers -- helping with access to needed services and problems that may be daunting to the older adult or their caregiver," said study senior author Michael LaMantia, M.D., MPH, an IU Center for Aging Research and Regenstrief Institute investigator and an IU School of Medicine assistant professor of medicine. "The CCAs also provide physicians and other members of the medical team with insight into how patients and their caregivers live and cope, helping the medical team provide high quality health care that

# What can we do to protect brain health?

...Mary G. Austrom, PhD

While there are no guarantees for how we will age, the latest findings suggest that some of these actions can help maintain brain health. Others are still being studied to see how they might affect brain health. We do know that doing these things is good for your health in general and they certainly can't hurt:

## Take care of your health

- Get recommended health screenings
- Manage health problems like diabetes, high blood pressure, and high cholesterol
- Consult with your health care provider to make sure your medicines are right for you
- Reduce risk for brain injuries due to falls, and other types of accidents
- Quit smoking

## Eat healthy foods

- Fruits and vegetables
- Whole grains
- Lean meats, fish, poultry
- Low-fat or non-fat dairy products
- Less solid fat, sugar and salt
- Proper portion sizes
- Adequate fluids

## Be active

- Physical activity may:
  - Reduce risks of diabetes, heart disease,

depression, and stroke

- Prevent falls
- Improve connections among brain cells
- Get at least 150 minutes of exercise each week.
- Move about 30 minutes on most days. Walking is a good start.
- Join programs that can help you learn to move safely.

Check with your health care provider if you haven't been active and want to start a vigorous exercise program.

## Learn new things

- Do mentally stimulating activities
- Read books and magazines
- Play games
- Learn new things
- Take or teach a class
- Be social through work or volunteering



## Connect with family, friends, and communities

- People who have meaningful activities, like volunteering, say they feel happier and healthier
- Social activities are linked to reduced risk for some health problems, including dementia
- Join in social and other programs through your Area Agency on Aging, Senior Center, or other community organizations.

## New low-cost workforce extends primary care....continued

(Continued from page 5)

addresses the specific needs and problems of each patient and their caregiver."

April 7, 2016—IndianapolisMedia contact: Cindy Fox Aisen, Regenstrief Institute; [caisen@iupui.edu](mailto:caisen@iupui.edu)

The study was funded by Centers for Medicare & Medicaid Services grant 1C1CMS331000-01-00. Drs. Austrom and Gao also were supported, in part, by NIH

P30 AG010133.

In addition to Drs. Austrom and LaMantia co-authors are Carly A. Carvell, M.D., and Sujuan Gao, Ph.D., of the IU School of Medicine; Catherine A. Alder, MSW, J.D., of the Regenstrief Institute, IU Center for Aging Research and Eskenazi Health; and Malaz Boustani, M.D., MPH, of the Regenstrief Institute, IU Center for Aging Research, IU School of Medicine and the Center for Health Innovation and Implementation Science.

# IADC Research: How you can become involved.

**What does participating in the Indiana Alzheimer Disease Center (IADC) at the Indiana University School of Medicine (IUSM) mean?**

**What happens if I sign up as a research participant at the IADC?**

**Screening:** We have a telephone screen in place that helps us get some background on the potential research participants. The screen collects some general information about health. Some existing health conditions, like a history of brain injury with loss of consciousness or a previous stroke disqualify participants as these types of health conditions damage the brain and will affect our ability to study how Alzheimer's disease and dementia affect the brain. If the potential research participant qualifies for participation they will receive a packet of forms and questionnaires to complete at home. If they have any trouble completing the forms we will help them at the in-person visit.

**Regular study visit:** This takes about 3 hours and includes a private visit with the research staff and a doctor who specializes in dementia diagnosis and care. They will collect general medical information and administer research questionnaires that will help us decide if the research participant has any changes in thinking and memory. The visit also includes a pen and paper test of memory and cognition (thinking). Finally, we will draw some blood as that helps us identify disease markers in blood. Wouldn't it be great to be able to diagnose AD with a simple blood test? During this visit the research participant has the opportunity to freely and privately communicate with the doctor and get any questions and concerns answered.

**Additional research procedures:** Additional research procedures are available to qualifying participants. The doctor and/or the research team will describe each procedure and discuss the following in more detail:

- **Research scan (magnetic resonance imaging)** – allows us to take a picture of the brain that tells us if any parts are shrinking or not working. The full protocol takes 1.5 hours; a shorter scan, 30 min long, is available but that only provides limited information.
- **Lumbar puncture** or spinal tap – a lot can be found in the fluid that bathes the brain. AD can be diagnosed with a lumbar puncture. There is so much to learn from this invaluable test.
- **Sensory testing** – includes detailed testing of vision, smell and hearing.
- **Other scans (like positron emission tomography or PET)** – we now have the opportunity to see the proteins that cause AD (positron emission tomography (PET) and tau) in the living brain. We have two types of research scans that will give us important information of how these proteins spread through the brain while the person with AD is still living.
- **Brain donation** – once the person with AD has passed, the opportunity to examine the brain under the microscope is vitally important as it improves our understanding of the disease compared to all the clinical information and scans we have collected.

All research procedures can be scheduled on **one day or two different days** if you would like. All participants **must have a study partner** – a spouse, a child, a close friend, another family member – that knows them well and can accompany them to the visit with the doctor (i.e., the 3-hour-long regular study visit). The study partner does not have to stay for the pen and paper testing, the imaging tests or the sensory testing but is welcome to do so.

**Please call Donna Wert at 317-963-7297 if you would like to learn more about getting involved with research.**

# Are you interested in learning more?

Are you interested in learning more about the Indiana Alzheimer Disease Center? Complete this form to get started!

**Please complete this form if you would like a phone call to get more information about the IADC. You may also use this form if you are interested in volunteering for research or for any of the other service you might be interested in...see the list below and check all that apply. Thank you.**

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

Phone: \_\_\_\_\_

Email: \_\_\_\_\_

Age: \_\_\_\_\_ years

Gender:  
 Male  Female  \_\_\_\_\_

Race:  White;  
 Black;  
 Asian;  
 Pacific Islander;  
 Native American  
 Mixed Races  
 Other (specify) \_\_\_\_\_

Ethnicity:  
 White Hispanic;  
 Black Hispanic;  
 Non-Hispanic  
 Other (specify) \_\_\_\_\_

**Languages: check all that apply:**

\_\_\_\_\_ I can speak, read and write English  
\_\_\_\_\_ I only speak English  
\_\_\_\_\_ I can speak, read and write another language (please specify) \_\_\_\_\_  
\_\_\_\_\_ I only speak another language (please specify) \_\_\_\_\_

**We are happy to help you learn about our other services. Check all that apply:**

\_\_\_\_\_ Please add me to your mailing list.  
\_\_\_\_\_ I am interested in research participation.  
\_\_\_\_\_ I am interested in diagnostic services. \_\_\_ self or \_\_\_ family member  
\_\_\_\_\_ I am interested in learning more about brain donation.  
\_\_\_\_\_ I am interested in supporting the IADC and its programs.  
\_\_\_\_\_ Please call me regarding \_\_\_\_\_.  
\_\_\_\_\_ I prefer to be contacted by (check one): \_\_\_\_\_ email \_\_\_\_\_ phone \_\_\_\_\_ mail

Scan and email this form to [dwert@iupui.edu](mailto:dwert@iupui.edu); fax it to 317-963-7325 or mail it to: IADC, Attention: Outreach, Recruitment and Education Core (OREC), 355 West 16<sup>th</sup> Street, Suite 2800, Indianapolis, IN 46202-7176.

## IADC Current Studies on AD and Related Disorders Research Enrolling Participants



People over the age of 65 are at an increased risk for dementia. At the Indiana Alzheimer Disease Center we are working to combat this devastating disease. Our research studies are looking for new ways to detect brain changes early to help develop treatments and investigating new avenues to understand the cause of Alzheimer's disease and other dementias.

If you have normal memory, are concerned about your memory, or have a diagnosis of mild cognitive impairment or mild Alzheimer's disease, and are interested in helping our research study, please contact us about an opportunity to become involved in our cutting-edge research.

We are looking for adults 65 and older with normal cognition or mild to moderate memory difficulties for brain imaging studies of memory at the IU School of Medicine. The study involves participating in at least three sessions, 12 months apart, and includes brain scans, a blood draw, and cognitive testing. Each session will be completed in 1-3 days and every effort will be made to work around individual schedules. Some of your evaluation results can be made available to you and/or your doctor. For more information please contact the Indiana Alzheimer Disease Center at 317-963-5500 or via e-mail at [iadc@iupui.edu](mailto:iadc@iupui.edu).

Please call Donna Wert at 317-963-7297 or email [dwert@iupui.edu](mailto:dwert@iupui.edu) to as about participation in any of the IADC research studies (pages 9-11).

The IADC team is collaborating with existing resources and registries such as [ResearchMatch](#), a free, national recruitment registry funded in part by the National Institutes of Health (NIH); the [Alzheimer's Prevention Registry](#), part of the NIH-supported Alzheimer's Prevention Initiative; and the Alzheimer's Association's [TrialMatch](#) service.

### Is Alzheimer Disease in your family photo?

If there are two or more living members of your family suffering from serious memory loss, our researchers may be interested in your family.

Please contact the National Cell Repository for Alzheimer Disease, (NCRAD) to learn more about this research opportunity.

E-mail NCRAD at [alzstudy@iupui.edu](mailto:alzstudy@iupui.edu) or or call 1-800-526-2839.

Visit the NCRAD website at [www.ncrad.org](http://www.ncrad.org)

# IADC Current Studies on AD and Related Disorders Research Enrolling Participants

For which study?	Who is needed?	Length of study?
IADC Clinical Core cohort	Participants may be <ul style="list-style-type: none"> <li>• Cognitively normal or</li> <li>• Have a diagnosis of mild cognitive impairment or dementia (AD or other types of dementia)</li> </ul>	<ul style="list-style-type: none"> <li>• Longitudinal; over a lifetime or as long as a person is willing.</li> <li>• Visits include: neurological exam, cognitive evaluation, informant interview, and a blood sample; most participants will also receive an MRI scan; other optional procedures may be requested (lumbar puncture, sensory exam, PET scan, etc.)</li> <li>• Visits will occur every year.</li> </ul>
Research Registry/database used to capture data for self-referred volunteers and established clinic patients interested in participating in clinical research and drug studies, now and in the future.	To participate, volunteers must have a diagnosis of one of the following: <ul style="list-style-type: none"> <li>• Probable Alzheimer’s disease</li> <li>• Mixed Dementia</li> <li>• Mild Cognitive Impairment</li> <li>• Vascular Dementia</li> <li>• Lewy Body Disease</li> <li>• Parkinson Dementia</li> <li>• Frontotemporal Dementia</li> </ul>	<ul style="list-style-type: none"> <li>• Information regarding research projects will be disclosed prior to enrollment in specific research studies.</li> <li>• Length varies by individual study.</li> </ul>
The Genetics of Late Onset Alzheimer’s Disease (LOAD) Study	Participants need to: <ul style="list-style-type: none"> <li>• Be a member of family with 3 or more living siblings diagnosed with probable AD.</li> </ul>	<ul style="list-style-type: none"> <li>• Longitudinal; over a lifetime or as long as person is willing.</li> <li>• Visits include: neurological exam, cognitive evaluation, informant interview and a blood sample for DNA at first visit.</li> </ul>
The National Cell Repository for Alzheimer’s Disease (NCRAD)	Participants need to: <ul style="list-style-type: none"> <li>• Be part of a family with two or more living members with AD or symptoms of serious memory loss;</li> <li>• Be eager to involve new families from all locations.</li> </ul>	<ul style="list-style-type: none"> <li>• Longitudinal; over a lifetime or as long as person is willing.</li> <li>• Visits are done by telephone or mail.</li> </ul>
FYN: A phase 2a, multicenter study of 18F—FDG PET, safety, and tolerability of AZD0530 in patients with mild AD	Participants need to: <ul style="list-style-type: none"> <li>• MMSE score of 18–26 points</li> <li>• Ages 55–85 years</li> </ul>	<ul style="list-style-type: none"> <li>• Up to a 42 day screening period</li> <li>• 52 weeks of treatments</li> <li>• Compensation:               <ul style="list-style-type: none"> <li>• Study medication, procedures, and exams provided without cost.</li> <li>• Compensation for time and travel provided.</li> </ul> </li> </ul>

# IADC Current Studies on AD and Related Disorders Research Enrolling Participants

(Continued from page 10)

For which study?	Who is needed?	Length of study?
Dominantly Inherited Alzheimer Network (DIAN) Longitudinal Study	<p>Participants need to:</p> <ul style="list-style-type: none"> <li>• Have a first degree relative with Alzheimer's disease caused by a known mutation;</li> <li>• Be at least 18 years of age;</li> <li>• Speak and read English;</li> <li>• Have someone who knows them well and is willing to answer questions about their memory and thinking.</li> <li>• Be 15 or more years younger than the estimated age of onset.</li> </ul>	<ul style="list-style-type: none"> <li>• In person, visits every 2 years, as long as the person is willing;</li> <li>• Visits include: neurological exam, cognitive evaluation, PET and MRI imaging, informant interview, blood draw and spinal tap.</li> </ul> <p>Compensation:</p> <ul style="list-style-type: none"> <li>• Travel, meals, completion of some procedures, and accommodations.</li> </ul>
Eisai: A placebo-controlled, double-blind, parallel-group, dose regimen-finding study to evaluate safety, tolerability, and efficacy of BAN2401 in subjects with early AD, defined as mild cognitive impairment due to AD.	<p>Participants need to:</p> <ul style="list-style-type: none"> <li>• Be 50-90 years of age;</li> <li>• AChEIs and/or memantine allowed if stable dose for at least 12 weeks prior to baseline;</li> <li>• Have a BMI &lt; 35 at screening;</li> <li>• Have a MMSE 22+.</li> </ul>	<ul style="list-style-type: none"> <li>• Up to 41 months</li> <li>• Average visit 3-6 hours</li> </ul> <p>Compensation:</p> <ul style="list-style-type: none"> <li>• varies from \$50 to \$100 visit; up to \$2600 maximum.</li> </ul>
INI: Therapeutic effects of intranasally-administered insulin (INI) in adults with amnesic mild cognitive impairment (aMCI) or mild Alzheimer's disease (AD)	<p>Participants need to:</p> <ul style="list-style-type: none"> <li>• Be 55 – 85 years of age (inclusive)</li> <li>• MMSE <math>\geq</math> 20</li> <li>• Have reliable study partner (caregiver who can come to study visits)</li> </ul>	<ul style="list-style-type: none"> <li>• Study participation is approximately 18 months.</li> <li>• During this study volunteers and their caregivers will need to complete approximately 11 study visits at the center.</li> <li>• Average length of study visit is 3-6 hours.</li> </ul>
A4 LZAZ ADC -040 Study: An Anti-Amyloid Treatment in Asymptomatic Alzheimer's disease research study to assess the effects of Solanezumab (LY2062430) versus Placebo in slowing cognitive decline in preclinical AD.	<p>Participants need to:</p> <ul style="list-style-type: none"> <li>• Be 65-85 years of age;</li> <li>• Have an MMSE score of 27-30 if more than high school education;</li> <li>• Have an MMSE score of 25-30 if only high school education;</li> <li>• Amyloid pathology present at screening</li> <li>• Be living independently;</li> <li>• Have a study partner accompany you.</li> </ul>	<ul style="list-style-type: none"> <li>• Receive monthly IV infusion of Solanezumab or placebo;</li> <li>• Visits are 3-6 hrs;</li> <li>• Approx. 164 weeks;</li> <li>• Clinic visit every 4 weeks.</li> </ul> <p>Compensation:</p> <ul style="list-style-type: none"> <li>• \$50 for each completed clinic visit;</li> <li>• \$75 for optional lumbar puncture at visit #5;</li> <li>• \$125 for final visit of optional lumbar puncture;</li> <li>• Complimentary parking.</li> </ul>

Please call Donna Wert at 317-963-7297 or email [dwert@iupui.edu](mailto:dwert@iupui.edu) to ask about participation in any of the IADC research studies (pages 9-11).

# **INDIANA UNIVERSITY STUDY INFORMATION SHEET FOR**

## **Amyloid PET Questionnaire for persons with memory loss/ early stage dementia/FTD/and caregivers**

You are invited to participate in a research study of **the use of Amyloid PET imaging**. You were selected as a possible subject because **you are either an individual with memory loss, early stage dementia or are a caregiver for such a person**. We ask that you read this form and ask any questions you may have before agreeing to be in the study.

The study is being conducted by **Dr. Liana Apostolova, Indiana University (IU), Department of Neurology**.

### **STUDY PURPOSE**

The purpose of this study is to **obtain the thoughts and feelings of individuals who might be interested in receiving an amyloid PET and use that data to apply for research grant funding**.

### **PROCEDURES FOR THE STUDY:**

If you agree to be in the study, please click on the link to the IADC website below and answer a seven question anonymous survey. <http://iadc.medicine.iu.edu/research/amyloid-pet-questionnaire>

### **RISKS AND BENEFITS**

The risks of participating in this research are being uncomfortable answering the survey questions. There is no risk of loss of

confidentiality, as we will not collect any personal data or information. **You are not expected to benefit from participating in this research.**

### **CONFIDENTIALITY**

There is no risk of loss of confidentiality, as we will not collect any personal data or information.

### **CONTACTS FOR QUESTIONS OR PROBLEMS**

For questions about the study, contact the researcher Dr. Liana Apostolova at 317-963-7436.

For questions about your rights as a research participant or to discuss problems, complaints or concerns about a research study, or to obtain information, or offer input, contact the IU Human Subjects Office at (317) 278-3458 or [for Indianapolis] or (812) 856-4242 [for Bloomington] or (800) 696-2949.

### **VOLUNTARY NATURE OF STUDY**

Taking part in this study is voluntary. You may choose not to take part or may leave the study at any time. Leaving the study will not result in any penalty or loss of benefits to which you are entitled. Your decision whether or not to participate in this study will not affect your current or future relations with IU.

# IDEAS — New IU Health Alzheimer's disease-related initiative

## **Imaging Dementia - Evidence for Amyloid Scanning (IDEAS) Study,**

investigates the clinical benefit of amyloid imaging. Participating physicians will have the opportunity to order amyloid imaging for patients meeting the study criteria and determine the presence of Alzheimer's type pathology in the brain.

### Requirements:

- Medicare beneficiary (65+ years of age)
- Diagnosis of mild cognitive impairment or dementia verified by a dementia expert within 24 months
- Meets appropriate use criteria for amyloid PET imaging:
  - Cognitive complaint verified by objectively confirmed testing
  - Etiologic cause of cognitive impairment is uncertain after a comprehensive evaluation by a dementia specialist
  - Alzheimer's disease is a diagnostic consideration
  - Knowledge of amyloid PET status is expected to alter diagnosis and management

### Details:

Three clinical visits:

- the comprehensive diagnostic examination to determine eligibility and to formulate a management plan before PET,
- the PET scan visit, and
- a follow-up visit to document the management that has been instituted once the PET results are known.

### Compensation:

Cost of the PET scans paid by CMS as a covered service for Medicare beneficiaries. As with any medical service covered by Medicare, participants will be responsible for any deductible or co-payment required for the service. The actual amount that the individual will pay will depend on their Medicare plan.

To refer a patient, or to learn more about the study, please call 317.963.7436.

IU is looking to recruit 200 plus individuals to help meet the goal of 18,000 subjects nationally.

# Memory University 2016

## Decision making and end of life care for dementia

May 19<sup>th</sup>, 26<sup>th</sup> and June 2<sup>nd</sup> and 9<sup>th</sup>, 2016

The Indiana Alzheimer Disease Center (IADC) presents **Memory University 2016**, a unique program for research participants, their family members and others interested in learning more about decision making and later stage Alzheimer's disease and other dementias. Attendees will learn the most up-to-date information about end of life care and have the opportunity to participate in Q&A sessions with our experts in the field.

**Memory University 2016** will be offered on four **Thursdays, May 19<sup>th</sup>, May 26<sup>th</sup>, June 2<sup>nd</sup> and June 9<sup>th</sup>**, at the IU Health Neuroscience Center, Goodman Hall Auditorium, 355 W. 16th Street, Indianapolis, Indiana 46202. Doors open at 1 p.m. and lectures start at 1:30. While **Memory University 2016** is free of charge, advanced registration is required. Register on-line at <http://iadc.medicine.iu.edu/current-events/memory-university-2016/> or for more information, call 317-963-7297 or email [dwert@iupui.edu](mailto:dwert@iupui.edu).

**May 19, 2016**

### *Using Indiana POST for Persons with Dementia*



**Lucia Wocial, PhD, RN, FAAN**, has been a registered nurse since 1985. Her current clinical practice is ethics. She serves as the nurse ethicist for Indiana University (IU) Health. She co-chairs the ethics consultation service at IU Health at the academic health center in Indianapolis. She is the project director for the Woltman Interprofessional Communication Scholars Program (WISP), a training program focused on improving communication around palliative and end-of-life care for teams of healthcare professionals. She is a researcher in Palliative and End-of-Life Communication and Training (RESPECT) Center, part of the Community & Health Systems and an Adjunct Assistant Professor at the IU School of Nursing.

**May 26, 2016**

### *Critical Decisions at the End of Life*

**Nicole R. Fowler, PhD, MHSA**, is an Assistant Professor with a primary appointment in the Department of Medicine, Division of General Internal Medicine and Geriatrics, and a scientist in the IU Center for Aging Research and Center for Health Care Innovation and Implementation. From 2010-2014 she was an Assistant Professor of Medicine at the University of Pittsburgh and the Associate Director of the University of Pittsburgh Alzheimer Disease Research Center Education Core.



**June 2, 2016**

### *Deciding on Medications in Dementia Care*



**Dan Bateman, MD**, is the Assistant Professor of psychiatry, Indiana University School of Medicine, Scientist, Indiana University Center for Aging Research, Investigator, Regenstrief Institute, Inc. and Implementation Scientist, Center for Health Innovation and Implementation Science. Dr. Bateman's research interests are in Alzheimer's disease, caregiver support for persons with dementia, implementation of best practices in dementia care, and use of technology to help older adults improve quality of life and maintain independence.

**June 9, 2016**

### *Grief and Bereavement*

**Mary Guerriero Austrom, PhD**, is the Wesley P. Martin Professor of Alzheimer Disease Education in the Department of Psychiatry; the Director of the Outreach, Recruitment and Education Core at the Indiana Alzheimer Disease Center; and the Associate Dean for Diversity Affairs at the Indiana University School of Medicine.



**SAVE THE DATES**



*Reflections*  
Spring 2016  
Volume 25 Issue 3

# *IADC 25th year Celebration!*

The Indiana Alzheimer Disease Center holds a Spring Scientific Symposium and a Fall Caregiver Symposium annually. This year, the two programs will be held together in recognition of the

## **IADC's 25th Anniversary Celebration**

**September 22, 2016**

**The IADC Annual Scientific Symposium**

**and**

**September 23, 2016**

**IADC Annual Martin Family Alzheimer Disease Caregiver  
Symposium**

**IU Health Neuroscience Center**

**Goodman Hall Auditorium**

Please check our [website](#) for additional program details.

Registration forms will be available soon.

**Like and follow us on**



**Facebook**

[www.facebook.com/IndianaAlzheimerDiseaseCenter](http://www.facebook.com/IndianaAlzheimerDiseaseCenter)



**Twitter**

[twitter.com/INAlzDiseaseCtr](https://twitter.com/INAlzDiseaseCtr)

# For the Caregiver... Communication Strategies for People with Dementia

Many caregivers tell us that trying to communicate with a family member with dementia is one of the most challenging things for them. And that is quite understandable, given, that as a culture, we rely on the spoken language to communicate. Thus, as language ability deteriorates, caregivers find themselves at a loss. Understanding some simple basics about how to improve communication for as long as possible and learning alternative ways to engage with your family member with dementia can be very helpful. Below are some tips to help you communicate with someone who has moderate to severe dementia. Remember, no strategy works 100% of the time, just try your best.

1. **Be realistic.** Alzheimer's disease (AD) and many related dementias, by definition are degenerative, which means that they will get worse with time. People with dementia will gradually have a more difficult time understanding others, as well as communicating in general.
2. **Avoid distractions.** Try to find a place and time to talk when there aren't a lot of distractions, such as noise, large groups, or other activities. This helps your family member to focus all their mental energy on the conversation. People with AD or dementia are easily distracted because they cannot filter out unimportant stimuli in the environment.
3. **Speak clearly and naturally in a warm and calm voice.** Refrain from "talking down" to a person with AD or dementia. If they look confused, try repeating the sentence or information again, using the same words, because changing words quickly may confuse them further. If they appear frustrated because they don't understand or can't get you to understand, calmly move on to something else.
4. **Use people's names.** Avoid pronouns like "he," "she," and "they" during conversation because pronouns can be confusing since they are not very specific. Names are also important when greeting someone with dementia. For example, say "Hi, Grandma. It's me, John," instead of, "Hi. It's me." Identifying yourself can help orient the person.
5. **Keep it simple.** Someone with dementia may not be able to juggle several ideas or themes in a complex conversation, so keep it simple and help them to know when the topic is changing. For example, say, "I want to tell you what the dog did yesterday."
6. **Use nonverbal cues.** Maintaining eye contact and smiling can put your family member at ease and will help comprehension. If the person looks away, looks down, wants to walk away, simply stop and try to figure out what they might need. In cases of advanced disease, people with AD will no longer be able to use words, so reading to them, listening to favorite music, books on tape, and other soothing things are helpful.
7. **Use active listening skills.** If you don't understand something your loved one is telling you, politely let them know that you didn't understand and ask them to repeat it or show you what they mean.
8. **Don't argue.** Do not try to correct every little error or misstatement that a person with AD or dementia makes. Simply put, it is not that important to make them understand your reality. It is so much more important to help them stay engaged with family and friends and to meet them "where they are" at any given moment.
9. **Have patience.** Give your family member with dementia extra time to process what you say. If you ask a question, give them moment or two to respond. Most people do not enjoy silence and quickly fill it in with another question. Counting to 10 slowly in your head will feel like forever, but often the other person will start talking first.
10. **Understand there will be good days and bad days.** While we know that people with AD and dementia will decline, they also have ups and downs just like anyone else. Take advantage of the good days and go easy on the bad days.

Adapted from a [PlaceforMom Senior Living Blog](#).  
Visit the [IADC resource page](#) for the IADC caregiver tip sheets on communication. More information on communication can also be found at [alz.org](#).

# For the Caregiver... Incontinence and Help with Toileting

A person with Alzheimer's disease (AD) may have other medical problems over time that can cause more confusion and behavior changes. Unfortunately, due to AD, often the person cannot tell you what is wrong. One common problem many older people have is incontinence, the lack of control over one's bladder and/or bowels. This may also happen at any stage of AD, but it is more often a problem in the later stages. Signs of this problem are leaking urine, problems emptying the bladder, and soiled underwear and bed sheets. Let the doctor know if you see any of these signs. He or she may be able to treat the cause of the problem.

## Causes of Incontinence

Incontinence has several possible causes and some can be treated.

- ◆ Urinary tract infection
- ◆ Enlarged prostate gland
- ◆ Too little fluid in the body (dehydration)
- ◆ Diabetes that isn't being treated
- ◆ Taking too many water pills
- ◆ Drinking too much caffeine
- ◆ Taking medicines that make it hard to hold urine

When you talk to the doctor, be ready to answer the following questions:

- ◆ What medicines is the person with AD taking?
- ◆ Does the person leak urine when he or she laughs, coughs, or lifts something?
- ◆ Does the person urinate often?
- ◆ Can the person get to the bathroom in time?
- ◆ Is the person urinating in places other than the bathroom?
- ◆ Is the person soiling his or her clothes or bed sheets each night?
- ◆ Do these problems happen each day or once in a while?

Here are some ways you can deal with incontinence:

- ◆ Remind the person to go to the bathroom every 2 to 3 hours. Don't wait for him or her to ask. Some people find it helpful to keep a record of how much food and fluid the person with AD takes in and how often he or she goes to the bathroom. You can use this information to make a schedule for going to the bathroom.
- ◆ Show the person the way to the bathroom or take him or her.

- ◆ Watch for signs that the person may have to go to the bathroom, such as restlessness or pulling at clothes and respond quickly.
- ◆ Make sure that the person wears loose, comfortable clothing that is easy to remove.
- ◆ Limit fluids after 6 p.m. if problems happen at night. Do not give the person fluids with caffeine, such as sodas, coffee or tea.
- ◆ Give the person fresh fruit before bedtime instead of fluids if he or she is thirsty.

Here are some other tips that can help:

- ◆ Mark the bathroom door with a big sign that reads "Toilet" or "Bathroom."
- ◆ Use a stable toilet seat that is at a good height. Using a colorful toilet seat can help the person identify the toilet. You can buy raised toilet seats at medical supply stores.
- ◆ Plan ahead if you are going out with the person. Know where restrooms are located. Take an extra set of clothing in case of an accident.
- ◆ Help the person when he or she needs to use a public bathroom. This may mean going into the stall with the person or using the family bathroom.

**Accidents will Happen.** Be understanding when bathroom accidents occur. Stay calm and reassure the person if he or she is upset. Incontinence supplies, such as adult disposable briefs or underwear, bed protectors, and waterproof mattress covers, may be helpful. You can buy these items at drugstores and medical supply stores. A drainable pouch may be useful for the person who can't control his or her bowel movements. Talk to a nurse about how to use this product.

For more caregiving tips and other resources:

- ◆ Read "Caring for a Person with Alzheimer's Disease" [www.nia.nih.gov/alzheimers/publication/caring-person-alzheimers-disease](http://www.nia.nih.gov/alzheimers/publication/caring-person-alzheimers-disease)
- ◆ Visit [www.nia.nih.gov/alzheimers/topics/caregiving](http://www.nia.nih.gov/alzheimers/topics/caregiving)
- ◆ Call the ADEAR Center toll-free: 1-800-438-4380
- ◆ IADC Caregiver tips [http://iadc.medicine.iu.edu/index.php/download\\_file/view/87/273/](http://iadc.medicine.iu.edu/index.php/download_file/view/87/273/)

Adapted from e-Update from the Alzheimer's Disease Education & Referral Center, a service of the National Institute on Aging at NIH, 1-26-16.

# Resources and Links for Caregivers

Below are Web links with descriptions highlighting practical resources you can print or download at no cost. The web sites contain much more information than we can include here. Surf the net and find some useful information. Please visit the IADC webpage often for this and many other [resources](#):

---

## Indiana Alzheimer Disease Center

[iadc.iupui.edu/resources/caregiver-information/](http://iadc.iupui.edu/resources/caregiver-information/)

## Alzheimer's Association

[www.alz.org](http://www.alz.org)

Over 140 [publications](#) on all aspects of the disease are free to download. Health care professionals and families can access the [Alzheimer's Association Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes](#) which contain their official recommendations for dementia care. Visitors have access to information in other languages, including a bilingual [Latinos and Alzheimer's](#) portal and an [Asian](#) portal that includes resources in Chinese, Korean and Vietnamese. [TrialMatch](#)™ helps families locate clinical trials based on personal criteria. [Comfort Zone](#) uses the Internet and a device to track the location of a person with Alzheimer Disease. The "[Research Center](#)" presents an extensive portfolio of information for finding the latest research from around the globe, how to volunteer for clinical trials in your area, and more.

## Alzheimer's Disease Education and Referral Center (ADEAR)

[www.nia.nih.gov/Alzheimers](http://www.nia.nih.gov/Alzheimers)

This Web site includes information for consumers on Alzheimer disease from the National Institute on Aging. Notable are the booklets, fact sheets, newsletter and training programs available through the [publications](#) link on their home page. View a 4-minute captioned [video](#) showing the intricate mechanisms involved in the progression of Alzheimer disease in the brain. [Unraveling the Mystery](#), contains both basic and technical information on the scientific and social aspects of Alzheimer. Resources are available in English and Spanish.

## ClinicalTrials.gov

[clinicaltrials.gov](http://clinicaltrials.gov)

Identify regularly updated federally and privately funded clinical research with human volunteers. Locate information about a trial's purpose, who may participate, locations, phone numbers and whether a trial is still recruiting. Find information about participating in an Alzheimer Disease research study, see our [alz.org](#) section called [Participating in Clinical Studies](#).

## Family Caregiver Alliance (FCA)

[www.caregiver.org](http://www.caregiver.org)

FCA's [Publications](#) section includes fact sheets, newsletters, research studies, reports, policy briefs and more available for anyone needing information on caregiving or developing programs and services for families. The [National Center on Caregiving](#) provides a state-by-state, online guide to identify programs and services nationwide for anyone involved in caregiving. Materials are available in Spanish and Chinese.

## Four Pocket Films

[agingresearch.org/pocketfilms](http://agingresearch.org/pocketfilms)

Four brief films on Alzheimer disease written by David Shenk, produced by Alliance Aging Channel and MetLife, and narrated by David Hyde Pierce can be watched online or purchased inexpensively and include: *What is Alzheimer disease?* *Alzheimer disease: an urgent epidemic*; *Alzheimer disease: Race to the cure*; and *Alzheimer disease: a message for newly diagnosed patients and their families*.

## 'My Thinker's Not Working'

[www.aadmd.org/ntg](http://www.aadmd.org/ntg)

[www.rrtcadd.org](http://www.rrtcadd.org)

A national strategy for enabling adults with intellectual disabilities affected by dementia to remain in their community and receive quality supports. The plan, developed by the National Task Group on Intellectual Disabilities and Dementia Practices presents findings and recommendations on the impact of Alzheimer disease. It includes an overview of the population, challenges facing them, community services, education and training, financing, and possible solutions. It also provides an action plan for national, state, and local agencies and recommends a specific assessment tool for recognizing dementia in this special population.

## National Library of Medicine – MedlinePlus

[www.nlm.nih.gov/medlineplus](http://www.nlm.nih.gov/medlineplus)

MedlinePlus is a goldmine of health information. It also has extensive information about drugs, an illustrated medical encyclopedia, interactive patient tutorials and health news. Pages related to dementia and dementia care are: [Alzheimer Disease](#), [Dementia](#), [Alzheimer's Caregivers](#) and [Memory](#). The Information is also available in Spanish: [Enfermedad de Alzheimer](#), [Demencia](#), [Proveedores de atención al paciente con Alzheimer](#), [Memoria](#). Additionally, MedlinePlus [email updates](#) deliver messages about new sites on MedlinePlus along with other notices. You can sign up to receive general emails covering all health topics, or you can sign up to receive emails about specific topics, like Alzheimer disease.

## NIH Senior Health – Alzheimer's Disease

[nihseniorhealth.gov/index.html](http://nihseniorhealth.gov/index.html)

If you are a computer savvy senior, or even if you're not, search the National Institutes of Health Web site on [eating well as you get old](#), [exercise for older adults](#), [talking with your doctor](#), [Alzheimer disease](#), [home care](#), [residential care](#), [caregiver support](#), [safety issues](#), [participating in clinical trials](#), and more. View the pages in different options like font size, contrast, speech capability, and printer friendly versions.

# In Memory....

The Indiana University Alzheimer Disease Research Fund gratefully thanks and acknowledges the following individuals for their generous contributions.



**In memory of W. Kirby Glazier:**

Barbara and Kirby E. Glazier

**In memory of Louise Gordon and Amy Burris:**

Jana Powell

**In memory of James P. Hauck:**

Christopher J. Hauck

**In memory of Carl Himebrook:**

Osburn, Hine, Yates & Murphy LLC  
Lacy Foundation

**In memory of Barbara Humnicky:**

Michael S. Humnicky  
Dena J. Young

**In memory of Kyle R. Jennings:**

Sandy J. and William E. Abston  
Chris N. and Laurie A. Herrell  
Jeffrey C. and Linda D. McLaughlin  
Cheryl A. and Darrel D. Moyer  
Martha A. and Rusty L. Parker  
James G. and Jenny Talbot  
Kristiane and Michael Tutts  
Anna D. and Jon Xanders

**In memory of Harry O. Johnson:**

Jayne M. Johnson Scheele  
Roger L. Scheele

**In memory of Frances M. Mallin:**

Ann L. Steigerwald

**In memory of Janet E. Paul:**

Martha J. Shockley

**In memory of Reg Primeau:**

Richard R. and Diane Primeau

**In memory of Steven F. Ross:**

Nancy R. Ross

**In memory of Marjorie A. Shedd:**

Lu A. and Jeff Howerton

**In memory of Frances M. Stayton:**

Waubesa Intermediate Schools

**In memory of John E. Weyreter:**

William G. and Martha S. Batt

**In honor of "The Dinner Group":**

Candis S. Caywood

**Donors:**

Lyn K. Berkebile  
Michele Blair  
Jill A. and David A. Burris  
Brandon G. Derck  
Prodip K. Dutta, Ph.D. and Gouri Dutta  
Dennis R. and Debra M. Eckert  
James H. Ellis, M.D.  
Bradley S. Glazier  
Robin and William J. Gress  
Richard W. Henderson, M.D. and Paula J. Henderson

**Donors continued:**

James W. Kraft and Jean L. Kraft, M.D.  
Michael A. Kyle, M.D.  
Susan Crane Kyle  
Debomoy K. Lahiri, Ph.D. and Mithu Lahiri  
Bruce W. and Elizabeth J. Long  
Patrick E. Matoole, M.D.  
Gary W. and Karen B. Meade  
Shirley R. Norris  
George and Annie Sha  
Kenneth and Audra D. Sheets  
Donald E. and Kathleen Siders  
Mark A. Stern, M.D. and Cheryl D. Stern, D.D.S.  
Reynolds American Foundation  
Kimberly M. Richards  
Margaret M. Redling  
Michele L. Reynolds  
Andrew J. Saykin, Psy.D. and Gwen Sprehn, Ph.D.  
Frederick W. Unverzagt, Ph.D. and Karen L. Unverzagt  
Lee A. Vriesman  
Sophia Wang  
Crystal White  
Thomas R. and Kathleen A. Wolfram  
Heun Y. Yune, M.D.

For more information on making a bequest or planned giving to the Indiana Alzheimer Disease Center you may also call 317-963-7599 or email

[bsglazie@iupui.edu](mailto:bsglazie@iupui.edu)

To use a credit card to make a gift, please go to our secure website at

[iadc.iupui.edu/give-now/](http://iadc.iupui.edu/give-now/)

Please make checks payable to:  
Indiana Alzheimer Disease Center

Mail to: Brad Glazier, Administrator  
Indiana Alzheimer Disease Center  
Indiana University School of Medicine  
IU Health Neuroscience Center, Suite 4100  
355 West 16th Street  
Indianapolis, IN 46202

## Important Findings from our Neuroimaging Research Team

A recent project explored amyloid PET imaging in patients with one of two mutations of the prion protein gene (*PRNP*) that cause Gerstmann-Straussler-Scheinker (GSS) disease, including the *PRNP* F198 mutation and the *PRNP* P102 mutation. GSS presents with motor and cognitive dysfunction and patients show deposition of prion protein amyloid (PrP-amyloid) and in some cases tau neurofibrillary tangles on autopsy. Our researchers wanted to determine whether an amyloid PET tracer called [<sup>11</sup>C]PiB would be sensitive to the PrP-amyloid in GSS. We observed no specific binding of [<sup>11</sup>C]PiB in the brains of asymptomatic mutation carriers or a symptomatic mutation carrier, despite the high likelihood of PrP-amyloid deposition in the symptomatic carrier. In fact, PrP-amyloid was observed in the brain of the symptomatic carrier on neuropathologic analysis approximately 4 years after the PET scan. Ultimately, this study suggests that [<sup>11</sup>C]PiB is insensitive to the PrP-amyloid found in GSS.

Deters KD, Risacher SL, Yoder KK, Oblak AL, Unverzagt FW, Murrell JR, Epperson F, Tallman EF, Quaid KA, Farlow MR, Saykin AJ, Ghetti B. [<sup>11</sup>C]PiB PET in Gerstmann-Sträussler-Scheinker disease. *American Journal of Nuclear Medicine and Molecular Imaging*. 2016 Jan 28;6:84-93



## Get Connected

Link to our Calendar: [iadc.iupui.edu/current-events/151/](http://iadc.iupui.edu/current-events/151/)

### FTD Caregiver Support Group

Has a loved one been diagnosed with frontotemporal dementia (FTD)?

Do you have questions about the disease and how to manage it?

You are not alone.

The IADC FTD Caregiver Support Group meets  
the **2nd Tuesday of each month from 6:30–8:30 pm.**  
at Joy's House Adult Day Services, 2028 E. Broadripple Avenue, Indianapolis, IN.

Joy's House Adult Day Service may provide a caregiver for patients with FTD and related disorders, so families can bring the patient with them, if necessary. *However, you must confirm with us ([dwert@iupui.edu](mailto:dwert@iupui.edu) or 317-963-7297) by 11:00 am on Monday prior to the meeting.*

**THANK YOU** to Joy's House Adult Day Services for providing a comfortable and confidential meeting place.



# IADC is Out and About

Faculty and staff from the IADC Outreach, Recruitment and Education Core (OREC) and other Cores attend many community programs, health fairs and conferences in central Indiana and beyond. Faculty have also been seen and heard on radio and TV programs around the area.

## CAREGIVER CROSSING

A Joy's House radio program

Caregiver Crossing can be heard on WIBC 93.1, Saturday mornings from 7–8 am.

Dr. Austrom is a guest speaker several times throughout the year.

Access mp3 podcast archives by going to the link below:  
<http://iadc.medicine.iu.edu/resources/caregiver-information/>

## alzheimer's association®

THE BRAINS BEHIND SAVING YOURS.™

AAIC videos are now posted and available on the Alzheimer's Association YouTube channel.

Here's a link: Women #ENDALZ is a series that profiles the amazing brains fighting to create a world without Alzheimer's disease. In this video, meet Alzheimer's researcher Shannon Risacher, Ph.D.

Celebrate your amazing brain today at [alz.org/mybrain!](http://alz.org/mybrain!)

[Women #ENDALZ: Shannon Risacher, Ph.D.,](#)

[Indiana University](#) Mar 4, 2016

A link to the full playlist for other videos on that day: [Women #ENDALZ: Alzheimer's Researchers](#)



Above: Saturday, 4/9/16 – “A Day Away”  
(Joy’s House sponsored event)

Welcome to our 30th Annual Conference



### Bringing Compassion to Action

Learn more about the Indiana Continuity of Care Association @ IN-COC.org

Left: Wednesday, 4/13/16 —

30th Annual Conference —  
Indiana Continuity of Care



Above: Saturday, 4/23/2016 – “Brain and Beyond Fair” –  
Smell tests; 3D Imaging, posters and more



Above: Tuesday, 4/26/2016 –  
Mary G. Austrom, PhD, presents at Money Smart Week event at the JCC

Right: Friday, 5/6/2016;  
Alzheimer’s Association Education Conference.

Daniel Bateman, MD, presents

“Driving and Dementia in Indiana”



If you have a program approaching, please contact the IADC by email at [dwert@iupui.edu](mailto:dwert@iupui.edu) or call 317-963-7297.

## Faculty and Staff News

**We want you to know us!**



Madeline E. Cassidy, MS

The IADC welcomes Madeline Cassidy who will be working with families as the Hereditary Disease Coordinator. Madeline Cassidy grew-up in Kokomo, IN and received her Bachelor of Science degree from Butler University in 2014, with a major in Biology. While at Butler, she was a committed athlete on the varsity track and field team, and very passionate about volunteer work at Riley Children's hospital and several other health organizations throughout the community. Madeline began her graduate degree in 2014 at Indiana University- Purdue University Indianapolis. During this time, she also enrolled in the accelerated nursing program at Marian University and completed the required nursing pre-requisite courses to strengthen her health sciences background. In 2015, she graduated from IUPUI with a Pre-Professional Master's degree from Purdue University in biology and health sciences. After graduation she worked at Dermatology Inc. assisting in Mohs micrographic surgeries and melanoma excisions. Madeline is excited to be serving as the new Hereditary Disease Coordinator at Indiana University, and we are excited to have her here!



Yvonne Lu, PhD, RN

Congratulations to Dr. Yvonne Lu, Associate Professor in the Department of Science of Nursing Care at the Indiana University School of Nursing and Co-Investigator in the IADC Outreach, Recruitment and Education Core, on receiving the 2016 Mary and John Barron Quality of Life Investigator Research Award from the IU School of Nursing. Dr. Lu's work focuses on improving the quality of life of patients with mild cognitive impairment and early Alzheimer's disease and their caregivers.



Ryan Crosbie

Please join us in thanking Ryan Crosbie for 6 years of service to the IADC! Ryan joined the center as a tester shortly after graduating from Purdue University. He was awarded his Clinical Research Certification after passing the SOCRA exam and, in time, worked his way up to serve as Coordinator for the Clinical Core. He has been a great resource to patients and families in addition to being a well-loved colleague.

We are happy to report that Ryan will not be going far! He will be leading research into treatments for Diffuse Lewy Body Disease and remain here at IU. Our sincere thanks go out Ryan for his tireless efforts for the IADC and we wish him the best of luck in his new endeavor!

# Get Dancing.....

Numerous studies have shown the positive impact that exercise can have on cognition and the brains of older adults. It has been suggested that dance may provide even more cognitive benefits because of factors that some other types of exercise may lack, such as cognitive stimulation, emotional impact, and social engagement. Recently, researchers reviewed available studies on the impact of dance on brains and cognition to determine the ways in which dance can impact older adults' cognition in addition to more widely recognized benefits related to balance, posture, gait, and falls prevention.

Some of the studies compared the cognitive performance of experienced dancers with non-dancers, and the majority of the results showed that the experienced dancers showed better cognitive performance on tests of attention, concentration, and intelligence. In addition, in a study in which older adults were randomly assigned to a dance group and a non-dance group, the dance group showed significant cognitive improvements in attention, concentration, intelligence, non-verbal learning, and memory after six months of weekly one-hour dance classes. Different studies on the impact of aerobic dance and Turkish folk dance showed that participants in both types of dance courses showed higher quality of life scores and greater happiness than control groups who did not take either class.

Studies of the cognitive impact of dance on individuals with dementia were also reviewed. These showed cognitive improvements in visuospatial ability and planning, as well as improved mood and emotional reactions.

Generally, these studies showed that dance benefits cognition and mood, as well as motor skills performance. By adding dance classes and opportunities to dance to all levels of continuing care in senior living, providers offer residents an enjoyable means of getting physical, emotional, and mental benefits.

Source: Kshtriya S, Barnstaple R, Rabinovich DB, et al. Dance and aging: a critical review of findings in neuroscience. <http://link.springer.com/article/10.1007/s10465-015-9196-7/fulltext.html>

*Reflections* is published by the Indiana Alzheimer Disease Center

**Administrative** Core Leader:

Andrew Saykin, PsyD

**Clinical** Core Leader:

Martin R. Farlow, MD

**Neuropathology** Core Leader:

Bernardino Ghetti, MD

**Data Management** Core Leader:

Sujuan Gao, PhD

**Outreach, Recruitment & Education** Core Leader:

Mary Guerriero Austrom, PhD

**Neuroimaging** Core Leader:

Andrew Saykin, PsyD

**Genetics, Biomarker & Bioinformatics** Core Leader:

Tatiana Foroud, PhD

**Contributors in this issue:**

Mary Guerriero Austrom, PhD

**EDITOR**

Mary Guerriero Austrom, PhD

**CO-EDITORS**

Andrew Saykin, PsyD

Brad Glazier

**EDITORIAL ASSISTANT**

Donna Wert

*The editor welcomes your comments and letters*

[maustrom@iupui.edu](mailto:maustrom@iupui.edu)

[dwert@iupui.edu](mailto:dwert@iupui.edu)