

INDIANA ALZHEIMER DISEASE CENTER  
INDIANA UNIVERSITY SCHOOL OF MEDICINE

# Reflections

## Increasing Education About, Awareness and Recruitment of Underrepresented Groups to Alzheimer's Disease Research: Working Collaboratively in the Community

...Mary Guerriero Austrom, PhD



Dr. Hugh Hendrie (center) with CAB Co-directors, Chris Campbell (left) and Ralph Richards (right).

Recently, the Indiana Alzheimer Disease Center Outreach and Recruitment Core (IADC OR Core) with the help and support of its Community Advisory Board (CAB) and the Alzheimer's Association of Greater

IN (AAGI) were successful in obtaining a grant to develop a community based collaborative program designed to:

1. increase education and awareness about Alzheimer's disease (AD) and available programs and services among traditionally underserved minority groups;
2. increase participation in AD research at the IADC by traditionally underserved minority groups; and
3. increase participation in the AA's TrialMatch®, a free, easy-to-use matching service that connects individuals with AD, caregivers, healthy volunteers and scientists with current research studies.

In central Indiana, traditionally underserved minority groups are African Americans and Hispanic/Latinos. While the US legislated the first ever National Alzheimer's Plan Act (NAPA) in 2013, with a goal to find a disease modifying treatment or preventive strategy by 2025, the lack of diverse participants in research is considered an obstacle in the successful search for such a treatment or cure. Because minority groups are not volunteering for research, at the same rates as Caucasians, even though some of them have a higher burden of risk for AD, it is difficult for researchers to generalize across study populations. The lack of minority groups in research is a national issue and all research is

challenged by such a lack of generalizability of results. This challenge contributes to the gap in translation from research to clinical care. Our project is a model of collaboration between our research center, a minority community group, as well as our IADC CAB, and a local chapter of the Alzheimer's Association that have similar missions.

Our project is a collaborative 12-month study that focuses on providing educational programs as a means to raise awareness about AD and to connect people to local resources and research. We have learned that most people do not understand AD and this itself is a barrier to participating in research. Our IADC CAB is represented by leaders from several service and faith based organizations and they meet monthly to offer recommendations and input into how to best develop educational and outreach initiatives. Most important, members of our CAB have reached out to other leaders in the minority community and helped us host educational programs, encouraged minority groups to get actively involved in both the IADC and to register with TrialMatch®. Our CAB has also helped with the recent production of brief video explaining the importance of research participation and what participation means to them. We are proud of our CAB and their commitment to the IADC and the research project. See pages 10 and 11 for photos from some recent joint activities. For more information on how to get involved in research at the IADC, contact 317-963-7297 or email [dwert@iupui.edu](mailto:dwert@iupui.edu).



IADC OR Core, our Community Advisory Board and the Alzheimer's Association of Greater Indiana working together to recruit more participants to research.

# Alzheimer's Caregiving Tips Helping Children Understand Alzheimer's Disease

When a family member has Alzheimer's disease (AD), it affects everyone in the family, including children and grandchildren. It's important to talk to them about what is happening. How much and what kind of information you share depends on the child's age and relationship to the person with AD.

## Helping Children Cope

Here are some tips to help children understand what is happening:

- Answer their questions simply and honestly. For example, you might tell a young child, "Grandma has an illness that makes it hard for her to remember things."
- Help them understand that their feelings of sadness and anger are normal.
- Comfort them. Tell them no one caused the disease.
- Give children information about AD that they can understand. For books and other resources, see [www.nia.nih.gov/health/resources-children-and-teens-about-alzheimers-disease](http://www.nia.nih.gov/health/resources-children-and-teens-about-alzheimers-disease)
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Talk with children about their concerns and feelings. Some may not talk about negative feelings, but you may see changes in how they act. For example, problems at school, with friends, or at home can be a sign that they are upset. A school counselor or social worker can help your child understand what is happening and can offer coping strategies.

A teenager might find it hard to accept how the person with AD has changed. He or she may find the changes upsetting or embarrassing and not want to be around the person. Don't force them to visit or spend time with the person who has AD. This can make things worse. Role model good interactions with the person with AD.

## Spending Time Together and Alone.

It's important to show children that they can still talk with the person with AD and help him or her enjoy activities. Doing fun things together can help both the child and the person with AD. Here are some things they might do together:

- Do simple arts and crafts projects
- Play music or sing
- Look through photo albums
- Read stories out loud
- Take walks in a garden or park.

If children live in the same house as someone with AD:

- Don't expect a young child to help take care of or "babysit" the person with AD.
- Make sure they have time for their own interests and needs, such as playing with friends, going to school activities, or doing homework.
- Make sure you spend time with them, so they don't feel that all your attention goes to the person with AD.
- Be honest about your own feelings when you talk with children, but don't overwhelm them.

If the stress of living with someone with AD becomes too great, think about placing the person with AD in a respite care facility. Then, both you and your children can get a much-needed break and spend some valuable time together.

## Helpful Resources:

- Read "[Caring for a Person with AD Disease](#)":
- Visit <https://www.nia.nih.gov/health/alzheimers/caregiving>
- Call the ADEAR Center toll-free: 1-800-438-4380
- **Alzheimer's Association**  
1-800-272-3900 (toll-free, 24/7)  
1-866-403-3073 (TTY/toll-free)  
[www.alz.org](http://www.alz.org)
- **Alzheimer's Foundation of America**  
1-866-232-8484 (toll-free)  
[www.alzfdn.org](http://www.alzfdn.org)
- **National Respite Locator Service**  
[www.archrespice.org/respitelocator](http://www.archrespice.org/respitelocator)
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## For Young Children:

- [Always My Grandpa: A Story for Children About Alzheimer's Disease](#) (by Linda Scacco, 2005, 48 p.)
- [Do You Have a Moon at Your House?](#) (by Jeannie Johnson, 2005, 39 p.) For ages 6–10.
- [Flowers for Grandpa Dan](#) (by Connie McIntyre, 2005, 32 p.)
- [Getting to Know Ruben Plotnick](#) (by Roz Rosenbluth, 2005, 32 p.)
- [Grandfather's Story Cloth](#) (by Linda Gerdner and Sarah Langford, 2008, 32 p.)

Adapted from National Institute on Aging "[Alzheimer's Caregiving Tips: Helping Kids Understand Alzheimer's Disease](#)".

## Memory University 2017: *Technology and Dementia Care*

Please visit our website [iadc.medicine.iu.edu](http://iadc.medicine.iu.edu) to review the sessions and find resources which were given on Friday afternoons in June 2017

The Indiana Alzheimer Disease Center presented Memory University 2017, a program for our research partners and others interested in Alzheimer's disease (AD) and other neurodegenerative diseases.

Memory University 2017 focused on *Technology and Dementia Care*. Attendees learned about technology and online programs to help with caregiving as well as information about avoiding investment fraud in the digital age.

### June 9<sup>th</sup>: Online Care Support

**Dan Bateman, MD**, is Assistant Professor of Psychiatry, Indiana University School of Medicine (IUSM), Scientist, Indiana University Center for Aging Research, Investigator, Regenstrief Institute, Inc. and Implementation Scientist, Center for Health Innovation and Implementation Science.

### June 16<sup>th</sup>: Healthy Aging Brain Technologies

**Richard J. Holden, PhD**, is Assistant Professor of BioHealth Informatics at the Indiana University School of Informatics and Computing, Indianapolis, and Director of the Health Innovation Lab ([theInnovativeU.com/lab](http://theInnovativeU.com/lab)).

### June 23<sup>rd</sup>: Guarding Against Investment Fraud

**Kelly Griese** is the Investor Education Coordinator for the Indiana Secretary of State and works to promote the Indiana MoneyWise program.

### June 30<sup>th</sup>: The Digital Age of Dementia Care

**Kristen Jenkins, MPH**, is the Information & Referral Manager for the Alzheimer's Association Greater Indiana Chapter.

### MEMORY UNIVERSITY 2017 RESOURCE LINKS:

#### Alzheimer's disease and dementia caregiver websites

- The Alzheimer's Association: [www.alz.org/](http://www.alz.org/)
- The Family Caregiver Alliance: [www.caregiver.org/](http://www.caregiver.org/)
- The Alzheimer's Reading Room: [www.alzheimersreadingroom.com/](http://www.alzheimersreadingroom.com/)
- AlzConnected: [www.alzconnected.org/](http://www.alzconnected.org/)
- Family Caregiver Alliance, CareJourney (online support groups): [www.caregiver.org/support-groups/](http://www.caregiver.org/support-groups/)

#### Caregiver Mobile Applications (Apps):

##### Information/Education Apps:

- Alzheimer's & Other Dementias [Daily Companion](#): Home Instead Senior Care®
- [Dementia Guide Expert for Families](#): University of Illinois
- Alzheimer's and Dementia Tips for Families: Peter Ericksen, HealthCare Interactive® [CARES](#)
- [Alzheimer's Disease Pocketcard](#) (Alzheimer's Association): Börm Bruckmeier Publishing
- [Alzheimer's Caregiver Buddy](#): Alzheimer's Association, Greater Illinois Chapter
- [Tender Loving Eldercare](#) – Family Caregiver's Guide: Linda Abbit
- [Balance](#): for Alzheimer's Caregiving: The Hebrew Home for the Aged

##### Caregiving Organization/Coordination:

- Senior Care Manager from Institute on Aging: [CareZone](#)
- Carely – Caregiving App for families: [Carely, Inc](#)

##### Peer-to-Peer:

- [Caregivers in the Community](#)™ (CINC): AARP Services Inc.

##### Self-Management:

- Woebot – Cognitive Behavioral Therapy ([www.woebot.io/](http://www.woebot.io/)) through Facebook messenger
- [Moodtrack Diary](#): Mood Tracker & Mood: Matthew Windwer
- [7 Cups](#) – Online Therapy for Anxiety and Depression
- [Pacifica](#) – Anxiety, Stress, & Depression Relief: Pacifica Labs Inc.
- [The Mindfulness App](#): Meditation for Everyone: MindApps
- [Relax Melodies Oriental Meditation](#): White Noise

##### Health Innovation Lab: [theinnovativeu.com/lab](http://theinnovativeu.com/lab)

##### Financial and Credit Protection Websites

Information on senior fraud or see if person/product is registered:

[www.Indianamoneywise.com](http://www.Indianamoneywise.com)

Indiana Attorney General's Consumer Protection Division

[Indianaconsumer.com](http://Indianaconsumer.com) State's one-stop resource-

Credit report—one free per year: [www.AnnualCreditReport.com](http://www.AnnualCreditReport.com)

Discontinue credit card offers sent to home:

[www.OptOutPrescreen.com](http://www.OptOutPrescreen.com)

Opt out of major online tracking companies for free:

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

Remove yourself from several mailing lists up to 5 years:

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

Federal Trade Commission: [www.FTC.gov](http://www.FTC.gov)

# Frequent, Brisk Walks May Help People with Early Alzheimer's Disease

For some people with early stage Alzheimer's disease (AD), frequent, brisk walks may help to bolster physical abilities and slow memory loss, according to one of the first studies of physical activity as an experimental treatment for dementia.

In a new study, published in February 2018 in PLoS One, Dr. Jill Morris and colleagues at the University of Kansas worked directly with people with a diagnosis of AD. Because the disease can affect coordination as it progresses, the researchers focused on men and women in with early stage AD, who were still living at home and could safely walk by themselves or perform other types of light exercise. Seventy (70) men and women with AD visited a lab at the university, where the scientists scanned their brains and tested their memories and thinking skills, aerobic endurance, and physical abilities, such as how well they could rise from chairs, lift objects and so on.

Then the volunteers were divided into two groups. One group began a supervised walking program that was supposed to raise their physical fitness. They walked progressively longer and faster over the course of several weeks, until they were briskly walking for at least 150 minutes each week. In earlier experiments, the Kansas scientists had found that this routine significantly improved aerobic endurance and memory performance among older people without AD.

The second group, serving as a control, began stretching and toning classes. These sessions were designed to be light exercise that would not increase aerobic endurance but would mimic the time commitment and social interactions of the walkers.

Both groups continued their regimens for six months and then returned to the lab for repeat testing. A few participants from each group had reported slight injuries and dropped out but most of them tolerated the exercise well.

Encouragingly, many showed improvement in physical functioning, particularly among the walkers. Almost all of them had significantly improved their scores on the tests of everyday physical skills. But the effects of the experiment on thinking and memory were more mixed. Most of those in the control group were slightly less able to think clearly and remember than they had been six months earlier. The toning had not slowed the progression

of their disease much, if at all. Similarly, many of the walkers performed no better and some scored worse on the cognitive tests than at the start.

But some of the walkers were thinking and remembering much better according to their cognitive tests six months later. These volunteers also generally showed slight increases in the size of their brain's hippocampus, the area of the brain affected early in the course of AD, whereas the other participants did not.

Trying to determine why some of the walkers showed benefits and others did not, the researchers delved more deeply into their data and found that the walkers who had increased their aerobic fitness had also improved their ability to remember and think and bulked up the volume of their brains. What surprised the scientists was how few of the walkers with AD had actually gained endurance. The same exercise program that previously had increased the aerobic capacity of almost every healthy, older participant now had benefits for the bodies of only a few of the walkers with AD.

This finding suggests that "there may be physiological differences between people with and without Alzheimer's that reach to the cellular level," says Dr. Morris. In effect, the bodies as well as the brains of people with AD may be unusually compared to those of healthy older people and may respond differently, if at all, to exercise, she says.

The positive news from her study, Dr. Morris points out, is that when people with AD did gain endurance, they also generally improved their ability to think and disease progression slowed as people's fitness rose. "It seems likely that the right exercise programs could be disease modifying," she says. "We just don't know yet what the ideal exercise programs are." Dr. Morris and her colleagues have studies underway and planned that look at many different types and amounts of exercise among people with AD.

Brisk walking is beneficial in general and is recommended for those with AD!

At IUSM and the IADC, Drs. Frederick Unverzagt's and Dan Clark's study, "Cognitive and Aerobic Resilience for the Brain (CARB, funded by the National Institute on Aging, R01 AG045157), is testing the effectiveness of

*(Continued on page 5)*

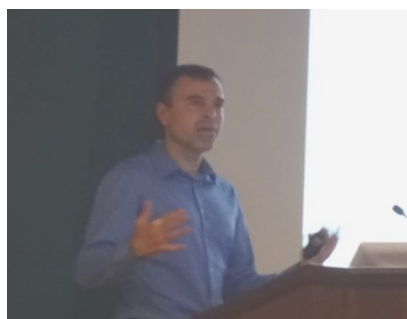


# IADC Welcomes Guest Speakers

James Leverenz, MD, Director, Cleveland Lou Ruvo Center for Brain Health and Joseph Hahn, M.D. Endowed Chair, Cleveland Clinic Neurological Institute, Cleveland, visited the IADC recently and presented to a large group of faculty, staff and trainees. His seminar was titled: *How Do You Define a Disease: Lessons from Neurodegeneration* and was very enlightening regarding how Parkinsonism, Lewy Body Dementia and Alzheimer's disease relate to one another.



James Leverenz, MD



Peter Bandettini, PhD

Dr. Saykin and the IADC hosted Peter Bandettini, PhD, Director, Section on Functional Imaging Methods, Laboratory of Brain and Cognition, National Institutes of Health, Bethesda, MD this spring. Dr. Bandettini's special lecture was titled *What further information can be extracted from time series fMRI data?*

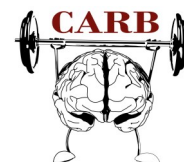
Over the years, researchers continue to develop novel MRI acquisition and processing methods to extract ever more subtle physiologic and neuronal information. Recently, time series fMRI has undergone a resurgence of interest with the explosion of resting state fMRI processing methods. His talk covered some of the more recent developments, including the use of novel approaches for

time series cleanup, the dynamics and stability of the resting state signal, as well as novel methods to probe activation-related signal. With regard to activation-related signal assessment, he discussed recent work in "decoding" ongoing mental processes using windowed pairwise correlation analysis, discovery of a wide range of non-canonical hemodynamic responses throughout the entire brain with only a relatively simple task, and finally, our most recent work using a non-invasive blood volume imaging technique known as VASO to differentiate layer dependent activity in somatosensory cortex. This layer dependent activity work potentially opens up a new avenue for fMRI to start looking not only at correlated activity but directionality of influence between regions and layers.

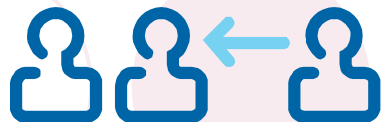
Dr. Bandettini is a pioneer and renowned expert on functional MRI, which is widely used in neuroscience research and in clinical practice for surgical mapping. His laboratory is on the leading edge of fMRI methods development. The IADC was pleased to host his visit.

(Continued from page 4)

physical and mental exercise on memory and cognition, function, and wellbeing in older adults with memory complaints. "In our project, we are building on the work of Dr. Morris and others that has shown the positive effects of exercise and brain training on thinking and memory. We hope that these behavioral and lifestyle interventions can improve a person's brain reserve capacity and, in that way, forestall dementia or at least push it back in time." The CARB study is a randomized clinical trial and is currently enrolling participants. For more details, go to [www.iu.edu/~carb/home.php](http://www.iu.edu/~carb/home.php) and [news.medicine.iu.edu/releases/2014/11/cognitive-training.shtml](http://news.medicine.iu.edu/releases/2014/11/cognitive-training.shtml). You may also contact the study team directly at 317-963-2561 or [carb@iupui.edu](mailto:carb@iupui.edu).



Portions of this article were adapted from The New York Times [nyti.ms/2ly5110](https://www.nytimes.com/2015/05/10/health/exercise-brain-training-memory.html)



**SAVE THE DATE!**  
**Get Connected...**

## 2017 IADC EVENTS

[iadc.medicine.iu.edu/](http://iadc.medicine.iu.edu/)



Check the IADC webpage and emails for updates for these 2017 IADC events:

### **IADC Upcoming Symposia**

**Program agendas and  
registrations available soon.**

**2017 IADC 11th Annual  
Martin Family**

**Alzheimer's Disease  
Caregiver Symposium  
*Transitions in Care***

**Friday, September 22, 2017**

### **Location:**

**IU Health Neuroscience Center  
Goodman Hall Auditorium  
355 W. 16th Street  
Indianapolis, IN 46202  
Entrance is at 362 W. 15th St.**

### **2017 IADC**

**Scientific Symposium  
*Gene Environment Interaction*  
Thursday, October 5, 2017**

### **Indiana 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  
**First Tuesday of each month from 6:30–8:30 pm** at  
Joy's House Adult Day Services, 2028 E. Broad Ripple 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 or 317-963-7297) by 11:00 am, Monday prior to the meeting.

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

# Why Purple?

...Donna Wert, OR Core Coordinator

## "Warning"

When I am an old woman I shall wear purple  
With a red hat that doesn't go, and doesn't suit me,  
And I shall spend my pension  
on brandy and summer gloves  
And satin sandals,  
and say we've no money for butter.

I shall sit down on the pavement when I am tired,  
And gobble up samples in shops and press alarm bells,  
And run my stick along the public railings,  
And make up for the sobriety of my youth.  
I shall go out in my slippers in the rain  
And pick the flowers in other people's gardens,  
And learn to spit.

You can wear terrible shirts and grow more fat,  
And eat three pounds of sausages at a go,  
Or only bread and pickle for a week,  
And hoard pens and pencils and beer mats  
and things in boxes.

But now we must have clothes that keep us dry,  
And pay our rent and not swear in the street,  
And set a good example for the children.  
We will have friends to dinner and read the papers.

But maybe I ought to practice a little now?  
So people who know me  
are not too shocked and surprised,  
When suddenly I am old  
and start to wear purple!

*Jenny Joseph*

My favorite color is purple ... any shade of purple. As most people touched by Alzheimer's disease know, the color purple is the signature color of the AD awareness ribbon and the Alzheimer's Association. A co-worker recently asked why the color purple is associated with AD. I did a little digging and found this to be the closest answer.

Jenny Joseph, an English poet wrote a wonderful "purple" poem in 1961 when she was thirty years old. It was not originally widely accepted in British publications but when it was printed in [the New York Times](#), it became a globally well-known and expressive icon of women's aging and freedom. In a poll by the BBC in 1996, her poem was voted as the most popular post-war poem ever published in British history.

The second line of her poem became the inspiration for the Red Hat Society that is popular world-wide. Love and laughter are the backbone of this club for ladies, delightful wearers of red hats and purple clothing along with other red accessories. Their society expresses the joy of life in self and others. If the poem had anything to do with the color purple as the color of the AD Awareness Ribbon remains unclear, but even if it had nothing to do with it, the poem is still wonderful.

By the way, as fair warning... I was presented with my own red hat at a previous birthday celebration.



The color purple is used for awareness of many causes including the following: ADD, ADHD, Alzheimer's, Animal Abuse, Anit-Violence, Arnold Chiari Malformation (alt teal), Chronic Pain, Colitis (alt blue), Crohn's Disease (alt blue), Cystic Fibrosis, Domestic Violence (Alt Teal & Purple), Epilepsy (alt Lavender), Fibromyalgia (alt Cranberry), Fibromyalgia in Men, GI Cancer (Intestinal), Harmony, Homelessness, Leiomyosarcoma, Lupus (alt orange), Macular Degeneration, Mesh Survivor, Mucolididoses, Neuropathy Awareness, No Unattended kids in Cars, Pancreatic Cancer, Pancreatitis (Chronic), Religious Tolerance, Rett Syndrome, Sarcoidosis, Sjorgren's Syndrome, Thyroid Cancer (alt specific ribbon) and Victims of 9/11.

Another list also included: Childhood Hemiplegia and stroke awareness; Craniosynostosis Awareness; Colitis Awareness Campaign; Elder Abuse Awareness; Hidradenitis Suppurativa Awareness Ribbon; March of Dimes; Meningitis Survivors; Premature Birth (Also Pink and Blue according to some organizations); Retinitis Pigmentosa; Spirit Day and victims of homophobia and Trisomy 9 Awareness.

## Volunteer for an Alzheimer's disease research registry!

Joining a registry or matching service can help advance research on Alzheimer's disease (AD) and dementia. You don't have to have AD to volunteer. Many registries and services are looking for healthy older adults and caregivers, too. Check out the links below of registries and services provided by the [NIH National Institute on Aging](#).

[Alzheimer's Prevention Registry](#)—Open to individuals age 18 and older who are interested in learning about and possibly participating in AD prevention clinical studies and trials.

[Brain Health Registry](#)—Open to individuals age 18 and older who want to promote healthy brain function by preventing brain diseases, disorders, and injuries. Take online tests, and learn about opportunities to participate in a wide range of studies.

[FTD Disorders Registry](#)—A contact and research registry for people diagnosed with FTD, and open to family members, caregivers, or friends of people diagnosed with FTD disorders.

[GeneMatch](#)—Open to adults ages 55 to 75 who are interested in enrolling in AD genetics studies.

[ResearchMatch](#)—A service, funded by the National Institutes of Health, that helps match people of all ages interested in clinical trials with researchers. Requires an email address.

[TrialMatch](#)—The Alzheimer's Association's clinical studies matching service for individuals with AD, caregivers, and healthy volunteers.

## Faculty and Staff News

### We want you to know us!



Priya Rajagopalan,  
MBBS, MPH,

**Priya Rajagopalan, MBBS, MPH**, Indiana University has been selected as one of several grant recipients of innovative research and education projects. The Radiology Society of North America Research and Education (RSNA R&E) Foundation. Her project, *Cerebral Perfusion Alterations in Cortisol Gene Carriers: A Potential Alzheimer's Disease Pathway*, will utilize a pulsed arterial spin labeling technique to investigate cerebral blood flow alterations associated with cortisol gene variants in subjects with mild cognitive impairment (MCI). Dr. Rajagopalan's project will enable discovery of novel genetic contributions to cognitive decline, hemodynamic alterations and brain atrophy related to stress and cortisol with a strong translational potential to identify novel therapeutic targets for Alzheimer's disease (AD) and enable enrichment for AD clinical trials.

Dr. Rajagopalan is featured in the Spring 2017 issue of *RSNA R&E Foundation Focus* with other 2017 R&E grant recipients. The grant recipients hail from 50 institutions across the globe. For a full list of the 2017 funded grants visit the [RSNA website](#).



# IADC Research: How can you 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 (MRI))** – allows us to take a picture of the brain that tells us if any parts are shrinking or not working. The full protocol procedure takes approximately 1.5 hours.
- **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 (PET))** – we now have the ability to see the proteins (amyloid and tau) that cause AD 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 4-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 our current research studies and getting involved with research.**

# IADC is Out and About

Faculty and staff from the Indiana Alzheimer Disease Center (IADC) including the Outreach and Recruitment Core (OR Core) attend many community programs, health fairs and conferences in central Indiana and beyond. Faculty have also been seen and heard on TV and radio programs around the area. Visit [iadc.medicine.iu.edu/](http://iadc.medicine.iu.edu/) for a list of upcoming events and stop by to meet faculty and staff from the IADC.



Bruce Lamb, PhD

Alzheimer's Awareness Day at the Indiana State House was Monday, March 13, 2017. Dr. Bruce Lamb, Roberts Family Chair in Alzheimer's Disease Research and Executive Director, Stark Neurosciences Research Institute at Indiana University School of Medicine, spoke on the *Cutting Edge Alzheimer's Research in Indiana* while attendees had opportunity to meet with their State Legislators.



A Day Away event was sponsored by Joy's House Adult Day Services at University of Indianapolis in April.

Lili Kyurkchiyska, Geneva Sanders and Donna Wert (not pictured) helped to host the IADC table.



Dr. Austrom presented to community members at the Concord Neighborhood Center in June 2017.



Caring for the Caregiver sponsored by Applegate Elder Law was held at Ritz Charles in April 2017 with Dr. Yvonne Lu presenting as one of the Keys to Caring panelists. Her key was **Learn** about your loved one's condition, advocacy, ask for help. The keynote speaker for the day was Amy Goyer, caregiver of many family members and author of *Juggling Life, Work and Caregiving*.

Below: Money Smart Week sponsored by the Indiana Association of Area Agencies on Aging and the Indiana Secretary of State featured a film on \$CAMMED and a Question and Answer Panel of experts including Dr. Mary Guerriero Austrom (2<sup>nd</sup> from left). Rafael Sanchez, Investigative Reporter for RTV6 was Master of Ceremonies in April 2017.



Above: Dr. Austrom recently presented at Harvard Medical School's *Dementia: A Comprehensive Update*.

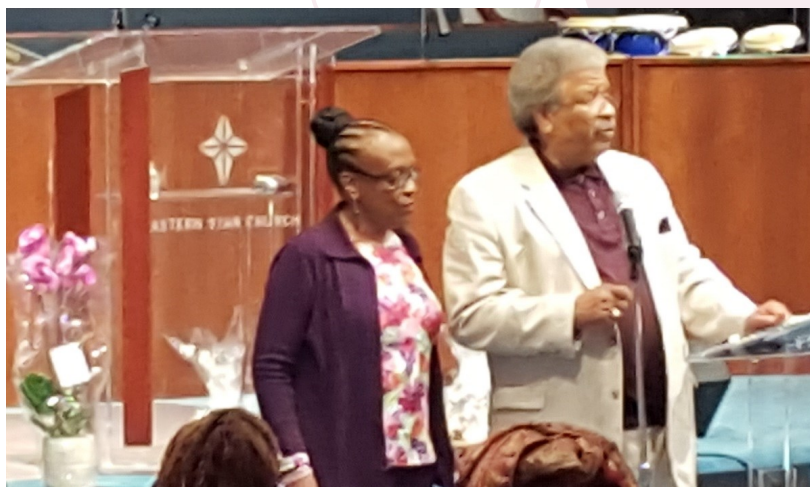


# IADC and our Community Advisory Board are Out and About

The Eastern Star Church and their Senior Saints Ministry hosted an *Alzheimer's Disease Awareness Session* at their main campus, June 17, 2017. The free session addressed early detection, self-care of the caretaker, legal rights, and more! A short memory screening and other resources were available to over 200 attendees.



JESUS EXALTED + WORD EXPLAINED  
EASTERN STAR CHURCH



Ralph and Mollie Richards, of the Indiana Alzheimer Disease Center's Community Advisory Board (IADC CAB), presented information regarding Alzheimer's disease and the need for minority communities to engage in research.



Left: Anita Harden, Elder Law Attorney, and IADC CAB member, encouraged the audience to be proactive in planning for the future using legal documents such as Last Will and Testament, Living Will, Health Care Power of Attorney, Financial Power of Attorney, Guardianship and Trusts.



Right: Dr. Mary Guerriero Austrom, IADC Outreach and Recruitment Core Leader, addresses the audience regarding how they can help by participating in research and why that is so important.

Right: The IADC and IUSM Student National Medical Association (SNMA) medical students conducted brief memory screenings. Pictured left to right: Olivia Simo MS3, McKenna Kirkwood, Dr. Mary Austrom, Cindy Abam MS2 and Donna Wert, IADC OR Core Coordinator.



Winners of the purple orchids were (left) Bernice Alexander and (right) Elvay Farries.



If you would like an IADC speaker for your upcoming event, please contact the IADC by email at [dwert@iupui.edu](mailto:dwert@iupui.edu) or call 317-963-7297.

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