iADC Reflections
Indiana Alzheimer Disease Center

Winter 2015

INDIANA ALZHEIMER DISEASE CENTER NEWSLETTER
INDIANA UNIVERSITY SCHOOL OF MEDICINE

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IADC Celebrates Twenty Five Years!

....Andrew Saykin, PsyD; Mary Austrom, PhD

The Indiana Alzheimer Disease Center (IADC) is in its 25th year of continuous National Institutes of Health funding, not an easy thing to achieve in the current extremely competitive climate of research funding.

The Indiana University School of Medicine (IUSM) has a long and distinguished track record of accomplishments in the field of neurodegenerative diseases. Interest in Alzheimer's disease (AD) research at IUSM can be traced back to the mid 1960s, when studies on familial AD and other adult onset dementias began in the Department of Neurology and Division of Neuropathology. These studies continued throughout the 1970s and 1980s. Over the past 30 years, the interest in the field has progressively grown and several investigators in the Departments of Psychiatry, Neurology, Pathology, Medicine, and Medical and Molecular Genetics joined in the studies of AD. With this growth, new resources had become available and in 1991, the IADC was funded by the National Institute on Aging (NIA). In 1993, the IADC was strengthened by the addition of the National Cell Repository devoted to the collection of immortalized cells from subjects affected by familial AD and related dementias. Over time, the IADC has undergone structural changes. First, the National Cell Repository Core was separated from the IADC into a stand-alone entity funded by the NIA in 2002. In 2004, the IADC competitively applied for and received funding for a Data Management and Statistics Core. The Data Core serves as the central repository for data collected by other IADC cores, and it is designed to provide analytical support to the research activities of the multidisciplinary IADC investigator team. In 2009, the IADC was awarded funds to establish a Neuroimaging Core. Important advances have been made in brain imaging and this core is important for identifying and implanting new biomarkers for dementia. Most recently, the IADC received an award to add a new Genetics, Biomarker and Bioinformatics Core. This new core focuses on collection and banking of blood and CSF biosample data and supports research on analysis of large amounts of complex data generated from genetic and biomarker studies. The original cores of the center remain unchanged including the Administrative, Clinical, Neuropathology and Education Cores. As research in the field has expanded at unprecedented rates, the recent areas of focus of the IADC have included behavioral neurology, clinicopathological correlations, biochemistry, and genetics of AD, frontotemporal dementia and

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The Connection between Down Syndrome and Alzheimer's Disease

...Mary G. Austrom, PhD

Many, but not all, people with Down syndrome develop Alzheimer's disease (AD) when they get older. AD is an irreversible, progressive brain disorder that slowly destroys memory and thinking skills and, eventually, the ability to carry out simple tasks.

AD is the most common cause of dementia among older adults. Dementia is the loss of cognitive functioning—thinking, remembering, and reasoning—and behavioral abilities to such an extent that it interferes with a person's daily life and activities.

People with Down syndrome are born with an extra copy of chromosome 21, which carries the amyloid precursor protein (APP) gene. Too much APP protein leads to a buildup of protein clumps called beta-amyloid plaques in the brain. By age 40, almost all people with Down syndrome have these plaques, along with other protein deposits, called tau tangles, which cause problems with how brain cells function and increase the risk of developing AD.

However, not all people with these brain plaques will develop the symptoms of AD. Estimates suggest that 50 percent or more of people with Down syndrome will develop dementia due to AD as they age into their 70s.

Alzheimer's Disease Symptoms

Many people with Down syndrome begin to show symptoms of AD in their 50s or 60s. But, like in all people with AD, changes in the brain that lead to these symptoms are thought to begin at least 10 years earlier. These brain changes include the buildup of plaques and tangles, the loss of connections between nerve cells, the death of nerve cells, and the shrinking or atrophy of brain tissue.

The risk for AD increases with age, so it's important to watch for certain changes in behavior, such as:

- increased confusion
- short-term memory problems (for example, asking the same questions over and over)
- reduction in or loss of ability to do everyday activities

Other possible symptoms of AD are:

- seizures that begin in adulthood
- problems with coordination and walking
- reduced ability to pay attention
- behavior and personality changes, such as wandering and being less social
- decreased fine motor control
- difficulty finding one's way around familiar areas

If you notice any of these changes, see a health care provider to find out more. Keep in mind, though, that not all dementia symptoms are caused by AD. Other conditions, such as medication side effects, depression, and kidney, thyroid, and liver problems, can also cause dementia symptoms. Some of these conditions can be treated and reversed that is why seeking medical attention early is so critical.

Currently, AD has no cure, and no medications have been approved to treat AD in people with Down syndrome.

Down Syndrome and Alzheimer's Disease Research

AD can last several years, and symptoms usually get worse over time. Scientists are working hard to understand why some people with Down syndrome develop dementia while others do not. They want to know how AD begins and progresses, so they can develop drugs or other treatments that can stop, delay, or even prevent the disease process.

Research in this area includes:

- Basic studies to improve our understanding of the genetic and biological causes of brain abnormalities that lead to AD.
- Observational research to measure cognitive changes in people over time.
- Studies of biomarkers (biological signs of disease), brain scans, and other tests that may help diagnose AD—even before symptoms appear—and show brain changes as people with Down syndrome age.

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Down Syndrome and Alzheimer's Disease

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- Clinical trials to test treatments for dementia in adults with Down syndrome. Clinical trials are best the way to find out if a treatment is safe and effective in people.

Participating in Research

New treatments, tests, and other discoveries would not be possible without volunteers who participate in clinical studies and trials. By volunteering, people can help others, receive care from medical providers, and possibly test new treatments.

Volunteers and their caregivers should consider a study's risks as well as its benefits. For example, a new drug being tested may have potential side effects. Researchers must follow federal and international rules to ensure that all participants are safe and that their personal information remains confidential. Study staff can explain safety and other issues and answer questions as you decide whether to participate in a research study or clinical trial.

Not everyone will be eligible to participate in every clinical trial. Studies have specific requirements that people must meet to participate. For example, participants must be of a certain age, have a certain diagnosis, or a specific genetic makeup. These requirements help ensure that the results of a study are reliable and useful.

Family members and other caregivers play an important role for adults with Down syndrome who participate in clinical research. They may be asked to provide consent or permission for the person with Down syndrome to take part in the study, accompany the person to study visits, and answer health questions about him or her. Researchers will explain the study in detail, describe all possible risks and benefits in a process called informed consent.

See the article on page 4 for information about a new NIH initiative on AD and Down Syndrome.

This article was adapted from https://www.nia.nih.gov/alzheimers/publication/alzheimers-disease-people-down-syndrome#connections . November 2015

Resources for More Information

Down Syndrome and AD

- An Introduction to Alzheimer's Disease (National Down Syndrome Society)
- A Caregiver's Guide to Down Syndrome & Alzheimer's Disease (National Down Syndrome Society)
- Down Syndrome and Alzheimer's Disease (Alzheimer's Association)
- Aging and Down Syndrome: A Health & Well-Being Guidebook (PDF, 8.0M) (National Down Syndrome Society)

Down Syndrome Research and Resources

- Down Syndrome Consortium
- Down Syndrome: Overview (National Institute of Child Health and Human Development)
- DS-Connect®: The Down Syndrome Registry
- LuMind Research Down Syndrome Foundation

Alzheimer's Disease Resources

- Alzheimer's Disease Education and Referral (ADEAR) Center (National Institute on Aging)
- Alzheimer's Association
- Alzheimer's Foundation of America

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NIH supports new studies to find Alzheimer's disease biomarkers in Down syndrome

...Mary G. Austrom, PhD

Groundbreaking initiative will track dementia onset and progress in Down syndrome volunteers

The National Institutes of Health (NIH) has launched a new initiative to identify biomarkers and track the progression of Alzheimer's disease (AD) in people with Down syndrome. Many people with Down syndrome have AD related brain changes in their 30s that can lead to dementia in their 50s and 60s. Little is known about how the disease progresses in this vulnerable group. The NIH Biomarkers of Alzheimer's Disease in Adults with Down Syndrome Initiative will support teams of researchers using brain imaging, as well as fluid and tissue biomarkers in research that may lead to effective interventions for all people with dementia.

The studies will be funded by the National Institute on Aging (NIA) and the *Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)*, both part of NIH. The institutes are jointly providing an estimated $37 million over five years to two highly collaborative projects, which enlist a number of leading researchers to the effort. To advance AD research worldwide, the teams will make their data and samples freely available to qualified researchers.

"This is the first large-scale Alzheimer's biomarker endeavor to focus on this high-risk group," said Laurie Ryan, Ph.D., chief of the Dementias of Aging Branch in NIA's Division of Neuroscience, which leads NIH research on AD. "Much like the long-established Alzheimer's Disease Neuroimaging Initiative, the goal of this initiative is to develop biomarker measures that signal the onset and progression of AD in people with Down syndrome. Hopefully, one day, we will also use these biomarkers to determine the effectiveness of promising treatments."

The link between AD and Down syndrome is well-known. People with Down syndrome are born with an extra copy of chromosome 21, which contains the amyloid precursor protein gene. This gene plays a role in the production of harmful amyloid plaques, sticky clumps that build up outside of the neurons in AD. Having three copies of this gene is a known risk factor for early-onset AD that can occur in people in their 30s, 40s and 50s. By middle age, most but not all adults with Down syndrome develop signs of AD, and a high percentage go on to develop symptoms of dementia as they age into their 70s.

The initiative establishes funding for two research teams that will pool data and standardize procedures, increase sample size, and collectively analyze data that will be made widely available to the research community. The teams will use several biomarkers to identify and track AD-related changes in the brain and cognition for over 500 Down syndrome volunteers, aged 25 and older. The measures include:

- Positron emission tomography (PET) scans that track levels of amyloid and glucose (energy used by brain cells); MRI of brain volume and function; and levels of amyloid and tau in cerebrospinal fluid and blood;
- Blood tests to identify biomarkers in blood, including proteins, lipids and markers of inflammation;
- Blood tests to collect DNA for genome-wide association studies that identify genetic factors other than the trisomy at chromosome 21 that may confer risk, or potentially protect against, developing Alzheimer's;
- Evaluations of medical conditions and cognitive and memory tests to determine levels of function and monitor any changes;
- For the first time in people with Down syndrome, PET brain scans that detect levels of tau, the twisted knots of protein within brain cells that are a hallmark AD.

Aside from earlier onset, AD in people with Down syndrome is similar to AD in others. The first symptom may be memory loss, although people with Down syndrome initially tend to show behavior changes and problems with walking.

"Over the past 30 years, the average lifespan of people with Down syndrome has doubled to 60 years—a bittersweet achievement when faced with the possibility of developing AD," said Melissa Parisi, M.D., Ph.D., chief of the NICHD Intellectual and Developmental Disabilities Branch, which leads NIH's Down syndrome research. "There is much to learn about AD in Down syndrome, and we're hopeful that these new projects will provide some answers. One mystery we hope to solve is whether or not the disease progresses at a faster rate in this group."

The research into AD in Down syndrome is a key focus of the National Plan to Address Alzheimer's Disease, which calls for improved care for specific populations that are unequally burdened by the disease, including people with Down syndrome, and for increased research that may lead to possible AD therapies.

Art Therapy and Dementia

...Juliet King MA, ATR-BC, LPC

Art therapy is a mainstream medical and healthcare profession that uses the creative process, art media, and resulting artwork to help people communicate. Art therapists are 'talk therapists' who use artwork and non-verbal expression to work with people as they explore their thoughts and feelings, reconcile emotional conflicts, foster self-awareness, manage behavior, develop social skills, reduce anxiety, increase self-esteem, and ultimately cope with challenging life circumstances. Art therapy has been shown to help with many neurological conditions such as Alzheimer's disease and dementia, and common goals include memory enhancement, movement rehabilitation, social engagement and increasing a sense of control in what may feel like helpless situations.

Often words are 'not enough' to explain how we think, feel, and perceive, and words become even less effective when the mind is compromised by disease. It is useful to have other ways to 'talk'; ways that don't initially rely on words to explain things. For example, colors, shapes, pictures, and symbols represent what we are experiencing and ultimately allow us to tell the stories of our lives and ourselves.

Although thoughtful research is helping us understand the intricacies of neurological conditions, the more we learn about the brain, it seems, the less we know. Art therapy is like a portal into these unknown areas. Creativity and imagination are healing and life enhancing--these processes hold great potential to assist in communicating even when other parts of the brain are not working. In the company of a trained art therapist, art becomes a bridge that keeps us connected with one another and ourselves.

Ms. King is the Director of Art Therapy and Assistant Professor at the Herron School of Art and Design at IUPUI and Adjunct Assistant Professor in the Department of Neurology at the Indiana University School of Medicine. She can be contacted at 317.278.5466 or email: kingjul@iupui.edu

For more information on art therapy, follow the links below:

American Art Therapy Association at www.arttherapy.org
Herron School of Art and Design www.herron.iupui.edu/art-therapy

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IADC is Out and About Again

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.

Dr. Shannon Risacher was a guest on Noon Edition of WFIU discussing developments in Alzheimer's Disease research and care. You can hear the July 30th broadcast here: http://indianapublicmedia.org/noonedition/developments- alzheimers-care-

On September 8th, Dr. Risacher was also a guest for the second segment on the online American Diabetes Association's program at HCTV (Hamilton County TV). The segment can be seen at either https://www.youtube.com/watch?v=zPQu4qJa3Ls or www.hamiltoncountytelevision.com/

Dr. Austrom was guest speaker to the American Diabetes Association — Diabetes Support group on September 15th.

Below: Panel discussion at Chocolate Sunday hosted by Alzheimer Association. Robert L. Russell, Sr., Brandy R. Matthews, Richard C. Mohs and Dr. Mary Guerriero Austrom. (Photo credit: Steven Aldrich. Reprinted with permission. Copyright 2015. Current Publishing, LLC.. All rights reserved.)

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/

If you have a program coming up, please let the IADC know; contact us by email at dwert@iupui.edu or call 317-963-7297.

Above: Too Sweet for Your Own Good Conference is a joint effort by National Kidney Foundation and Minority Health Coalition of Marion County.

Faculty and Staff News

Who is calling and asking all those questions?

Kala Hall

IADC research participants will be hearing a new voice on the phone. The IADC welcomes Kala Hall who joined the IADC team as the Clinical Core Scheduler in September. Kala worked in the Physics department for 4 years as an administrative assistant while attending school. She graduated in May of 2015 from Indiana University Purdue University Indianapolis with a Bachelor of Science in neuroscience and two minors, French and mathematics. While pursuing her degree, she held leadership roles at the IUPUI chapter of Best Buddies, a nonprofit organization dedicated to improving the lives of individuals with intellectual and developmental disabilities. The experience with Best Buddies inspired her to pursue a career in health advocacy. After reading the book Still Alice she ultimately knew that she wanted to be involved with Alzheimer's disease research. She stated that "As the IADC Clinical Core scheduler, I am excited to be working at a place so involved in research and to have daily interaction with people who have been impacted by this disease. One of the most enjoyable parts of my role is getting to know our research participants." You may be talking with Kala soon as she completes questionnaires, schedules, recruits, and helps in keeping the center running.

Elsa Carenduto

Elsa Carodenuto provides part-time administrative support to the Indiana Alzheimer's Disease Center at Indiana University School of Medicine. You may hear her over the phone to schedule your next research visit or she may be assisting you during your next clinic visit. She is passionate about helping others and being an advocate. Currently, she is completing her master's in School Counseling and Mental Health at Indiana University Purdue University Indianapolis. She has a Bachelor's Degree from Butler University in Psychology and German with a concentration in International Business. Her past work experience is in customer service and research; working at Target Headquarters as a systems administrator and completing 4 years of research at Butler University in autobiographical memory, in which she published 8 papers and presented at over 5 conferences. Elsa is native to Minnesota, and in her free time she teaches yoga, bakes, travels, and goes on hikes. She has studied abroad in Vienna, Austria twice (one year in high school and over a summer during college) and would love to go back again soon.

Eileen Tallman serves as a coordinator to the Neuroimaging Core. She works directly with volunteers having research PET and MRI scans for the IADC. She helps with phone screens and safety/eligibility assessment, scheduling for imaging procedures, and data management for the Neuroimaging Core. Eileen has a B.A. in English and a B.S. in Psychology. She has worked in research since 2008. In her free time, she watches anthology series or comedies, attends concerts, and writes.

Eileen Tallman

IADC says "Farewell" to Clinical Core staff

Katherine Johnson

Left: Katherine Johnson left the role of Clinical Core Scheduler to pursue a nursing degree.

Right: Melissa Wesson, coordinator of the DIAN study had an opportunity to join the Department of Medical and Molecular Genetics full time.

We wish both the best in their new ventures.

Melissa Wesson

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 screening in place that helps us get some background on the potential research participants. The screening 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. Please note and be assured that **any information collected during this and other visits, DO NOT BECOME PART OF MEDICAL RECORDS BUT IS KEPT STRICTLY PRIVATE AND CONFIDENTIAL.**

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 (amyloid beta 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 our research program.

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

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

Gender:
○ Male ○ Female ○ _____

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; fax it to 317-963-7325 or mail it to: IADC, Attention: Outreach, Recruitment and Education Core (OREC), 355 West 16th Street, Suite 2800, Indianapolis, IN 46202-7176.

IADC Current Studies on AD and Related Disorders Research Enrolling Participants

For which study?	Who is needed?	Length of study?	Please contact…
IADC Clinical Core cohort	Participants may be • Cognitively normal or • Have a diagnosis of mild cognitive impairment or dementia (AD or other types of dementia)	• Longitudinal; over a lifetime or as long as a person is willing. • 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.) • Visits will occur every year.	IADC 317-963-5500 iadc@iupui.edu
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: • Probable Alzheimer's disease • Mixed Dementia • Mild Cognitive Impairment • Vascular Dementia • Lewy Body Disease • Parkinson Dementia • Frontotemporal Dementia	• Information regarding research projects will be disclosed prior to enrollment in specific research studies. • Length varies by individual study.	Christina Brown 317-963-7426 chbrown@iupui.edu
The Genetics of Late Onset Alzheimer's Disease (LOAD) Study	Participants need to: • Be a member of family with 3 or more living siblings diagnosed with probable AD.	• Longitudinal; over a lifetime or as long as person is willing. • Visits include: neurological exam, cognitive evaluation, informant interview and a blood sample for DNA at first visit.	National Cell Repository for AD 1-800-526-2839 alzstudy@iu.edu
The National Cell Repository for Alzheimer's Disease (NCRAD)	Participants need to: • Be part of a family with two or more living members with AD or symptoms of serious memory loss; • Be eager to involve new families from all locations.	• Longitudinal; over a lifetime or as long as person is willing. • Visits are done by telephone or mail.	National Cell Repository for AD 1-800-526-2839 alzstudy@iu.edu

IADC Current Studies on AD and Related Disorders Research Enrolling Participants

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For which study?	Who is needed?	Length of study?	Please contact…
Dominantly Inherited Alzheimer Network (DIAN) Longitudinal Study	Participants need to: • Have a first degree relative with Alzheimer's disease caused by a known mutation; • Be at least 18 years of age; • Speak and read English; • Have someone who knows them well and is willing to answer questions about their memory and thinking. • Be 15 or more years younger than the estimated age of onset.	• In person, visits every 2 years, as long as the person is willing; • Visits include: neurological exam, cognitive evaluation, PET and MRI imaging, informant interview, blood draw and spinal tap. **Compensation:** • Travel, meals, completion of some procedures, and accommodations.	Christina Brown 317-963-7426 chbrown@iupui.edu
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.	Participants need to: • Be 50-90 years of age; • AChEIs and/or memantine allowed if stable dose for at least 12 weeks prior to baseline; • Have a BMI < 35 at screening; • Have a MMSE 22+.	• Up to 41 months • Average visit 3-6 hours **Compensation:** • varies from $50 to $100 visit; up to $2600 maximum.	Lyla Christner 317-963-7411 lychrist@iupui.edu or Christina Brown 317-963-7426 chbrown@iupui.edu
FYN: A phase 2a, multicenter study of 18F—-FDG PET, safety, and tolerability of AZD0530 in patients with mild AD	Participants need to: • MMSE score of 18–26 points • Ages 55–85 years	• Up to a 42 day screening period • 52 weeks of treatments **Compensation**: • Study medication, procedures, and exams provided without cost. • Compensation for time and travel provided.	Abby Klaehn 317-963-7440 aklaehn@iupui.edu
Lundbeck study, to assess benefits of adding Lundbeck study medication to patients already taking donepezil/Aricept	Participants need to: • Be at least 50 years of age • Have been diagnosed with probable Alzheimers disease with MMSE 12-22 • Have reliable caregiver who can come to study visits • Taking ONLY donepezil/ Aricept 10mg/day for 4 months • Not be taking Namenda	• 28 weeks with option of open label extension (where know you're getting study drug) of another 28-32 weeks	Caitlin Camp, RN 317-963-7369 cmcamp@iupui.edu

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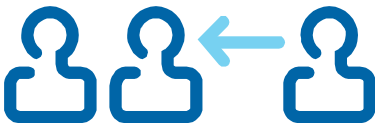
IADC Current Studies on AD and Related Disorders Research Enrolling Participants

For which study?	Who is needed?	Length of study?	Please contact…
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.	Participants need to: • Be 65-85 years of age; • Have an MMSE score of 27-30 if more than high school education; • Have an MMSE score of 25-30 if only high school education; • Amyloid pathology present at screening • Be living independently; • Have a study partner accompany you.	• Receive monthly IV infusion of Solanezumab or placebo; • Visits are 3-6 hrs; • Approx. 164 weeks; • Clinic visit every 4 weeks. **Compensation:** • $50 for each completed clinic visit; • $75 for optional lumbar puncture at visit #5; • $125 for final visit of optional lumbar puncture; • Complimentary parking.	Nancy McClaskey, RN, CCRP 317-963-7429; nmcclask@iupui.edu or Christina Brown 317-963-7426 chbrown@iupui.edu

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.



Link to our Calendar:
iadc.iupui.edu/current-events/151/

Get Connected

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. (West of Keystone at 62nd St.).**

Joy's House Adult Day Service provides a caregiver for patients with FTD and related disorders, so families can bring the patient with them, if necessary.

THANK YOU to our hosts and providers for a comfortable and confidential meeting place.

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/

Alzheimer's Association
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
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
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
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
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
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
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
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.

IADC Celebrates Twenty Five Years! .....continued

(Continued from page 1)

parkinsonism linked to chromosome 17 (FTDP-17), Gerstmann-Sträussler-Scheinker disease (GSS), Parkinson disease and other hereditary diseases associated with abnormal protein accumulation.

Over the past 25 years, the IADC has contributed significantly to the field of dementia research by the characterization of new diseases, the discovery of novel genetic mutations and characterization of the associated disease processes, and by the production and characterization of transgenic animal models.

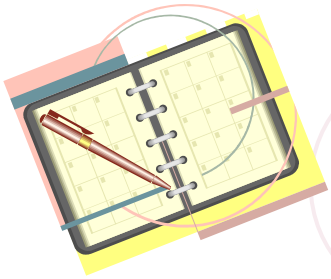
As we await news regarding continued NIH research support for the next 5 years, the IADC will build on past accomplishments and expand research in new directions. The newest cores, the Neuroimaging Core and the Genetics, Biomarker and Bioinformatics Core, represent important directions that extend prior studies to include early detection of AD and other dementias during the presymptomatic and minimally symptomatic stages of disease. This goal is extremely important for several reasons. First, recent studies that the IADC contributed to have shown that processes related to AD begin about two decades prior to dementia. Second, it has become increasingly clear that new drugs and other interventions are most likely to be effective very early in the disease process. Third, systematic data collection from individuals in these very early stages will facilitate a better understanding of the biological basis of AD and other dementias, and this in turn will foster development of new therapeutic approaches.

How will we accomplish these goals? The Clinical Core, which recruits and annually assesses research participants, will work with the Genetics, Biomarker and Bioinformatics Core to collect blood samples on all cohort members, as well as CSF whenever possible, for genetic and biochemical studies. The Neuroimaging Core will perform advanced MRI (magnetic resonance imaging) scans on all eligible participants. These scans include measures of brain structure, connectivity including white matter fiber tracts (the brain's "wiring system"), blood flow, and activity during rest and during memory tasks. In addition, some participants will be invited to participate in PET (positron emission tomography) scans that measure abnormal proteins in the brain including amyloid and tau – which form the plaques and tangles of AD. These tools have revolutionized dementia research by permitting detection of biological processes contributing to dementia very early in the course of AD and other disorders. Combining measures of genetic risk and protective factors with detailed information on brain health via advanced imaging and fluid biomarkers will provide the basis for a future personalized or precision medicine of brain aging and dementia.

These are just a few of the new directions and developments in the IADC. Another exciting development in the IADC renewal proposal is the addition of a Research Education Component (REC) that will be required of all AD centers. The REC is responsible for coordinating training activities in neurodegenerative disease research for graduate and medical students, as well as scientific career development for post-doctoral fellows and junior faculty. The IADC has long been facilitating the training of dozens of learners of all levels every year and the new REC formalizes and expands this important contribution to the future of translational neuroscience by training the next generation of researchers who will further accelerate progress in the battle against dementia.

Finally, and most importantly, a collaborative research team is made of people. In this issue, several new staff members are introduced. The IADC is extremely fortunate to have many new colleagues joining the IADC, some are new to IU and others are new to their roles in the IADC. In coming issues, we will introduce new behavioral neurologists, geriatric psychiatrists, basic and translational neuroscientists and others working on all aspects of dementia research and care. In the meantime, very best wishes for the holidays to our many friends of the IADC!

SAVE THE DATES



IADC celebrates 25 years!

The Indiana Alzheimer Disease Center is celebrating its

25th Anniversary!

Please save September 22nd and 23rd, 2016

and more details will be announced soon.

The IADC Annual Scientific Symposium and the

IADC Martin Family Alzheimer Disease Caregiver Symposium

will be held together next year.

IU Health Neuroscience Center

Goodman Hall Auditorium

Memory University 2016

May 19th and 26th and June 2nd and 9th, 2016

IU Health Neuroscience Center — Goodman Hall Auditorium

Each **Thursday** afternoon from 1:30 to 3:00 we will present a different topic of interest for anyone interested in learning more about brain health, dementia, Alzheimer's disease and other neurodegenerative disorders. Speakers and topics for discussion will be announced in the spring.

Coping Over the Holidays

Holidays can be meaningful, enriching times for both the person with Alzheimer's disease (AD) and his or her family. Maintaining family rituals and traditions helps all family members feel a sense of belonging and family identity. For a person with AD, this connection with a familiar past is both reassuring and can help trigger pleasant memories.

Some caregivers have mixed feelings about holidays. They have happy memories of the past, but they may worry about the extra demands that holidays make on their time and energy. It is important to find a balance between doing too many holiday-related activities and taking care of your own needs and those of the person with AD.

Below are some tips that can help you and the person with AD enjoy the holidays, reconnect with family and friends, and not get overwhelmed with all the activities.

- Celebrate holiday and events that are important to you. Include the person with AD as much as possible.
- Set limits, and be clear about them with others. You do not have to live up to the expectations of others. Your situation is different now so speak up and tell others.
- Involve the person with AD in simple holiday preparations, or have them observe your preparations. Watching you will familiarize them with the upcoming festivities. Participating may give the person the AD the pleasure of helping and the fun of anticipating and reminiscing. If the person with AD becomes overwhelmed or agitated, stop and redirect.
- Encourage friends and family to visit even if it's difficult. Limit the number of visitors at any one time, or have a few people visit quietly with the person with AD in a separate room.
- Prepare quiet distractions to use, such as a family photo album, if the person with AD becomes upset or overstimulated.
- Avoid situations that may confuse or frustrate the person with AD, such as crowds, big changes in routine, and strange places. Also try to stay away from noise, loud conversations, loud music, lighting that is too bright or too dark, and having too much rich food or drink (especially alcohol).
- Find time for holiday activities you like to do. If you receive invitations that the person with AD cannot attend, go yourself. Ask a friend or family member to spend time with the person while you're out.

Preparing Family and Friends

Explain to guests that the person with AD does not always remember what is expected and acceptable. Give examples of some behaviors that may take place such as memory loss, eating food with fingers, wandering, or hallucinations.

- If this is the first visit since the person with AD became severely impaired, tell guests that the visit may be difficult. The person with AD may not remember guests' names or relationships but can still enjoy their company.
- Explain that memory loss is the result of the disease and is not intentional.
- Stress that the meaningfulness of the moment together matters more than what the person remembers.

Preparing the Person with AD

- Begin showing photos of the guests to the person a week before arrival. Each day, explain who the visitor is while showing the photo.
- Arrange a phone call for the person with AD and the visitor. The call gives the visitor an idea of what to expect and gives the person with AD an opportunity to become familiar with the visitor.
- Keep routines as close to normal as possible.
- During the hustle and bustle of the holiday season, guard against fatigue and find time for adequate rest.
- Plan activities earlier in the day, rather than later.
- Keep visits short. Encourage family and friends to come by for short visits often, rather than one long visit.

Portions of this article was adapted from one posted by the Alzheimer's Disease Education and Referral (ADEAR) Center, a service of the National Institute on Aging, part of the National Institutes of Health. The Center offers information and publications for families, caregivers, and professionals about Alzheimer's disease and age-related cognitive changes. Visit the IADC website for more information on coping during the holidays.

Coping Over the Holidays

....continued

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
* **Visit** www.nia.nih.gov/alzheimers/topics/caregiving
* **Call** the ADEAR Center toll-free: 1-800-438-4380
* **Visit** IADC Website - http://iadc.medicine.iu.edu/resources/caregiver-information/ or
* **Call** the IADC at 317-963-5500

The IADC faculty and staff wish you a Joyous Holiday Season and Happy New Year!

INDIANA UNIVERSITY
INDIANA ALZHEIMER DISEASE CENTER
School of Medicine

Give Now!

See just how important your contribution is to supporting research and eventually finding the cure for Alzheimer's disease, Please view this short video by clicking the link below and see why Dianne Trauring and Nancy Carpenter chose to be donors.
www.youtube.com/watch?v=cQSB1pYVxsI&feature=youtu.be

Each year, the Indiana Alzheimer Disease Center is the grateful beneficiary of many memorial gifts to fund our Alzheimer Disease and Related Disorders research.

Visit the IADC webpage to find out more and then click the click here give now icon.

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

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

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

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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

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
dwert@iupui.edu