

Amyloid Deposits in Cognitively Normal People May Predict Risk for Alzheimer's Disease

Mary Guerriero Austrom, PhD and Martin R Farlow, MD

According to two studies done by researchers at Washington University, St. Louis, in persons free of dementia, abnormal deposits of a protein associated with Alzheimer disease (AD) are associated with increased risks of developing the symptoms of the progressive brain disorder. These studies, primarily funded by the National Institute on Aging (NIA), part of the National Institutes of Health, linked higher amounts of the protein deposits in dementia-free people with a greater risk for developing the disease, and with loss of brain volume and subtle declines in cognitive abilities.

The online issue of the Archives of Neurology, reported the two studies on the Dec. 14, 2009. The scientists used brain scans and other tests to explore the relationship between levels of beta-amyloid, a sticky protein that forms the hallmark plaques of AD, and dementia risk in cognitively normal people. John C. Morris, M.D., who directs the NIA-supported Alzheimer's Disease Research Center at Washington University, St. Louis, and his team conducted the research. Martha Storandt, Ph.D., also of Washington University in St. Louis, directed one of the studies.

AD pathology causes changes to the brain many years before memory loss, confusion, and other symptoms of the disease are apparent.

But it remains difficult to accurately predict whether a cognitively normal person will—or will not—develop the disease,” said NIA Director Richard J. Hodes, M.D. “These new studies suggest that beta-amyloid measured in the brains of cognitively normal individuals may be a preclinical sign of disease.”

John C. Morris, M.D. and his team used a variety of measures to look for changes in the brain in the two studies, including positron emission tomography (PET) imaging using a radioactive form of Pittsburgh Compound B (PiB), an agent specially developed to detect levels of beta-amyloid protein in the living brain; magnetic resonance imaging (MRI) to measure brain volume; and standardized clinical tests of memory and thinking abilities to determine cognitive health. Previously, the link between beta-amyloid load and AD could only be confirmed at autopsy.

The studies indicated that beta-amyloid might be present in the brain even in symptom-free people:

Between 2004 and 2008, researchers used PiB scans to track 159 volunteers ages 51 to 88, who started the study with no signs of cognitive impairment, to see if there was a correlation between beta-amyloid levels and cognitive health. Over time, 23 participants developed mild impairments, and nine were eventually diagnosed with clinical AD.

- Compared with participants who remained cognitively normal, the nine who were eventually diagnosed clinically with AD had high levels of PiB binding in the brain and experienced cognitive decline as well as volume loss in the parahippocampal gyrus, a part of the brain that controls memory. However, not every person who had beta-amyloid deposition in the brain developed cognitive impairment. Beta-amyloid deposition may be a risk factor for developing AD but its presence **does not** constitute a diagnostic finding.
- In 135 cognitively normal older adults aged 65 to 88, the level of beta-amyloid as measured by PiB binding correlated with atrophy, or shrinkage, in many parts of the brain and to declines on memory and thinking tests over many years.

Dr. Morris states, “More study is needed in larger groups (of people) for longer periods, but these studies confirm the value of detecting and measuring β -amyloid load in the brains of living people as soon as possible. These imaging tools are an important part of ongoing efforts to create a profile of AD in its earliest stages, even before symptoms appear, by linking imaging results with other biomarkers and clinical evaluations. “

Asked about the importance and relevance of these studies, **Dr. Martin Farlow, Professor, Department of Neurology and Director of the Clinical Core at the Indiana Alzheimer Disease Center here at Indiana University** explains: *These two studies by Dr. John Morris highlight the importance of β -amyloid deposits in the brain as a risk factor for cognitive impairment and eventual AD. In many ways, these studies suggest β -amyloid in the brain may be analogous to high cholesterol and heart disease. Elevated β -amyloid and elevated cholesterol are risk factors for AD and myocardial infarction respectively, but not significant enough alone to cause AD or myocardial infarction. Many people have elevated β -amyloid and elevated cholesterol but do not necessarily develop AD or myocardial infarction. The Morris studies point to potential early therapies aimed at preventing AD before it has a chance to start.*

Article adapted from NIA press release.

2010 iADC Annual Scientific and Martin Family Caregiver Symposia Were Successful

On March 19th and 20th the Indiana Alzheimer Disease Center hosted the its **3rd Annual Scientific Symposium** and the **4th Annual Martin Family Alzheimer Disease Caregiver Symposium**. Both programs were very successful. Dr. Bernardino Ghetti, iADC Director, welcomed participants and invited speakers, Drs. Herman Buschke, Christos Davatzikos, Douglas Galasko, Tom Montine, Jill Murrell, Ronald DeMattos, Eric Siemers and Paul Aisen, whose presentations discussed the symposium theme *Early Diagnosis and Biomarkers of Cognitive Decline*.

continued on page 13

Silver Alert System:

Keeping Persons with Alzheimer Disease Safe

Mary Guerriero Austrom, PhD, Wesley P Martin Professor of Alzheimer Disease Education
Department of Psychiatry and Director, Education Core, Indiana Alzheimer Disease Center

A growing number of states are adopting Silver Alert programs, an alert system that helps locate seniors with Alzheimer's disease (AD) who become lost. Modeled on the Amber Alert system, which is used to locate, lost or abducted children, the Silver Alert system is activated when someone with AD or another form of dementia goes missing. Alerts are sent out to local law enforcement, as well as radio and television stations and providing the name, license plate number, a photo, physical attributes and other vital identification information.

It is common for some people with AD to wander or drive off and become lost. Quickly locating the missing person is critical, since it is estimated that half of those who are not found in the first 24 hours will suffer serious injury or death. If someone with AD is reported missing, Silver Alerts are broadcast various ways. In addition to radio, TV and the Internet, electronic highway signs that normally convey traffic conditions can give the make and license plate number of the car that the person may be driving. Or, thousands of automated phone calls may go out to homes in the area where the person with AD went missing. Approximately 95 percent of people with AD who wander are found within a quarter-mile of their home or the last location seen.

While the Amber Alert system is now active in all 50 states, the Silver Alert program is just now gaining traction. Colorado was the first state to initiate the program, in 2006. Since then, Georgia, Illinois, Kentucky, Michigan, North Carolina, Oklahoma, Ohio, Texas, Virginia and Florida are among the states that have followed suit. The U.S. House of Representatives passed the National Silver Alert Act (H.R. 6064) in February 2009 but the Senate has not yet considered the bill. The bill, supported by the Alzheimer's Association, directs the Department of Justice to develop voluntary state guidelines for the development of Silver Alert plans, establish minimum standards for the issuance of alerts through the network, and make training and educational programs and materials available to states, local governments, law enforcement and other agencies. To date, the system has helped reconnect many lost dementia patients with family and friends.

While Silver Alert also increases awareness about wandering and can alert families to the possibility of future problems or the need for additional assistance if they have had to use the system, it is important for people to understand that the Silver Alert program is a system that coordinates law enforcement activities **after** a person with AD is missing. Preventing or reducing the risk of wandering and getting lost is better yet. A number of technologies are available now that can help people with AD and their caregivers minimize the chances of getting lost. A good place to start to decide which technology or program might be most useful for you is at the Alzheimer's Association's website www.alz.org where you can check out a new program called Comfort Zone. Comfort Zone and other services, like Safe Return, provide options for care partners and are part of a larger care plan for people with AD. Comfort Zone proactively communicates the location of the person with AD – either when that person cannot be located, or if there is a wandering incident and emergency assistance is needed. It prevents the sole reliance upon emergency responders to help families locate a missing person with AD or dementia.

Continued on page 4

The Alzheimer's Association also provides families and caregivers education on how to decrease the likelihood of wandering, as well as modifications that can be made in the home. Comfort Zone is one tool that, in combination with education and support, may reduce the incidence of wandering.

In addition, the Alzheimer's Association has emergency responder training material to help educate and build relationships with local law enforcement agencies in an effort to maintain safety for people with Alzheimer's disease and their families. To find out more about Comfort Zone and keeping persons with AD safe, check out www.alz.org or call 1-800-272-3900.

What To Do If Your Family Member with Dementia and Memory Loss Goes to the Hospital

Mary Guerriero Austrom, PhD

A trip to the hospital is stressful at the best of times but for a person with dementia or memory loss going to the hospital can be especially difficult because the hospital is usually a very busy, noisy and confusing place. Having a family member at the hospital is also stressful for the caregiver. This information can help you be prepared for an unexpected or a planned hospital visit. Below are some ideas to make the stay less traumatic and some tips for making the person with dementia more comfortable. Also included are suggestions on how to work with the hospital staff and doctors.

Be Prepared

Managing Emergencies

- Register the person with dementia in the Medic Alert/Alzheimer's Association Safe Return Program with your local Alzheimer's Association Chapter (see www.alz.org or call 1-800-272-3900). The program will speed up the process of reconnecting you with the person should they get lost.
- Identify family members you can depend on to stay with the person if they are admitted to the emergency room or hospital. Try to have at least two dependable family members, neighbors or friends you can call on in an emergency. It is helpful to have someone stay with the person with dementia at all times as a hospital can be very confusing and make their confusion worse. The person with dementia will need someone to help them, support them, and speak up for their needs.
- If possible, talk about options for care as the disease progresses. For example, if the person with memory loss can no longer participate in decision making, talk to your doctor about the best options for care if a medical emergency happens. Hospice care may be a better option or alternative to hospitalization at some point in the disease process.

Have an Emergency Bag Ready to Go Containing a Personal Information Sheet

- Prepare an overnight bag so that you don't have to worry about that in an emergency. Label it as the Emergency Bag and store it by the front door or in the trunk of the car.
- Include:
 - Cell phone
 - Information sheet that includes important phone numbers such as the family doctor, family and friends, rabbi, minister, priest etc.

Continued on page 5....

Hospitalization Happens (continued from page 4)

- Another good idea is to program these numbers into the cell phone

Paperwork or Documentation to Have Ready

- Insurance cards, policy numbers and pre-authorization phone numbers.
- Medicaid and/or Medicare cards
- Durable Power of Attorney, Health Care Power of Attorney, Living Will and/or DNR (do not resuscitate order)

Supplies for the Caregiver

- Change of clothes, toiletries
- Necessary prescription medications and pain medication such as Advil, Tylenol or aspirin just in case
- A pad of paper and pen to write down instruction, directions or to keep a list of symptoms or problems. It is hard to remember everything in a stressful situation.
- Sealed snacks such as water, crackers, or juice
- Small amount of cash or an ATM card

Being prepared can reduce **stress and confusion if an unplanned trip to the emergency room arises.**

How the Caregiver and Family Can Help:

- Offer physical and emotional comfort and verbal reassurance.
- Stay calm and positive. The way you feel will get picked up by others so keep them upbeat.
- Be aware that most emergency room staff has limited training in AD and related dementia so assist them in understanding the person and his or her needs.
- Encourage the staff to see the person as an individual and not just another patient with dementia who is confused and disoriented.
- **Do not assume** that person with dementia will be admitted to the hospital. Do not leave the emergency room without a follow-up plan and instructions on follow-up care.

With AD and Related Dementias, it is Important to Realize that Hospitalization Happens

- Enlist help. This is a perfect time to have one or two other family members there to help in a number of ways:
 - To make sure medications, and/or physical restraints are not used to control behaviors that can be managed with redirection or distraction.
 - To communicate with the person so they understand and know they won't be left alone.
 - To communicate with others in the family so you aren't distracted.
 - You are your family member's best advocate.
 - Unfamiliar places and faces, medicines, invasive tests, surgery and so on, can make a person with dementia more confused. They will likely need more assistance with personal activities so do not be alarmed about that.
 - Modify the hospital room for the person to insure ease and comfort, e.g., bring in some family photos, a favorite blanket, and music.

Continued on page 6....

Hospitalization Happens (continued from page 5)

- If you want to be the one who gives the person a bath or want to help with meals, let the hospital staff know and leave the request at the nurse's station.
- Help at mealtime by opening food containers, removing trays and filling out menus if necessary.
- Drinking fluids is important. Remind the person to drink or help them to drink.
- They may need frequent trips to the bathroom and assume they will have difficulty so be ready to assist them.
- Bring your own shampoo and soap from home if that is helpful. Familiar scents can have a calming effect.

No one knows your loved one like you do. Do not assume that the staff know or understand the person's behaviors

- Inform them in a polite, calm manner what the behavior means.
- Inform staff about hearing difficulties and/or any other communication
- Tell staff about previous issues with wandering, getting lost, falls, suspiciousness and/or delusional behavior such as hallucinations.

Before You Leave the Hospital:

- Ask the hospital discharge planner about eligibility for home health services equipment or long term care options.
- Be prepared for an increased level of caregiving after discharge.
- **Always ask questions when you do not understand procedures, tests or when you have any other concerns**

If the person with dementia experiences anxiety or agitation try

- Posting reminders or clues around the room if this comforts them.
- Turning off the TV, telephone ringer and intercom (if possible) to prevent overstimulation and minimize background noise.
- Speaking in a calm voice and offering constant reassurance. Repeat answers to questions as needed.
- Providing a comforting touch or distracting them with a favorite snack or beverage.
- Asking for a pain evaluation every four hours if their breathing is labored, they are moaning loudly, crying, and grimacing or if you are unable to console the person.
- Listening to soothing music or comforting ritual
- Avoid talking about subjects or events that may upset the person.
- Taking deep breaths and schedule some time for a brisk walk, a snack and short rests for yourself.

Helpful Resources:

Alzheimer's Disease Education Referral
(ADEAR) Center
800-438-4380
www.niania.gov/Alzheimers

Alzheimer's Association
800-272-3900
www.alz.org

Eldercare Locator
Family Caregiver Alliance
800-445-8106 (toll-free)
www.eldercare.gov

National Family Caregivers Association
800-896-(toll-free)
www.thefamilycaregiver.org

Current Studies on AD and Related Disorders Research Enrolling Participants

The iADC clinical faculty and staff conduct many clinical trials and research studies . Due to the rapid and ever changing nature of research, and enrollment criteria, it is easier for those interested in research to call Julie Dickson, who will review all the studies with potential clinical research participants.

Who is needed?	For which study?	Length of Study?	Please contact...
<p>To participate, volunteers must have a diagnosis of one of the following:</p> <ul style="list-style-type: none"> • Probable Alzheimer’s Disease • Mild Cognitive Impairment • Lewy Body Disease • Frontal Temporal Dementia • Mixed Dementia • Vascular Dementia • Parkinson’s Dementia 	<ul style="list-style-type: none"> • This Registry/database is used to capture data for self-referred volunteers and established clinic patients that have interest in participating in various clinical research studies now and in the future. 	<ul style="list-style-type: none"> • Information regarding research projects will be disclosed prior to enrollment in specific research studies. • Length varies by individual study. 	<p>Julie Dickson, RN 317-278-4333 or 866-257-0195</p>
<ul style="list-style-type: none"> • Health older adults • Diagnosed with mild to moderate memory difficulties • Spouse of care partner • Every effort will be made to work 	<ul style="list-style-type: none"> • Improving care of persons with Mild Cognitive Impairment (MCI) and their care partners 	<ul style="list-style-type: none"> • 3 months • Bi-weekly meetings • No cost skills training program • 4 data collection interviews • Compensation for time & free 	<p>Dr. Yvonne Lu, RN, PhD 317-278-2042 yuelu@iupui.edu</p>

Who is needed	For which study	Length of study	Please contact...
<ul style="list-style-type: none"> • Healthy older adults • With mild to moderate memory difficulties • 60 years of age + • Right-handed • Completed at least the 10th grade of education 	<ul style="list-style-type: none"> • Study of memory in health older adults • Study includes a brain scan, blood draw, eye exam and cognitive testing 	<ul style="list-style-type: none"> • 3-year study with 3 assessments 18 months apart • Each visit is 7-8 hours and can be scheduled over 2 days • Compensation for time and effort provided 	<p>Tamiko MaGee, MS 317-278-3121 tmagee@iupui.edu</p>
<ul style="list-style-type: none"> • African American family caregivers for persons w/AD-any stage • Caregiver (spouse, adult child, other) • Over 18 years old who has been the primary caregiver for at least 3 months 	<ul style="list-style-type: none"> • Anticipatory grief in African American caregivers 	<ul style="list-style-type: none"> • One Interview approximately 1 hour-long • Interview will be recorded • Complete a written questionnaire • Compensation provided upon completion 	<p>Susan McLennon, RN, PhD 352-318-4409 (cell) or 317-278-0459 smclennon@iupui.edu</p>
<ul style="list-style-type: none"> • Qualifying families with 2 or more living siblings diagnosed w/probable AD • Plus a 3rd family member who is either >60 yrs of not affected or >50 yrs with memory problems 	<ul style="list-style-type: none"> • The Genetics of Late Onset Alzheimer's Disease (LOAD) Study 	<ul style="list-style-type: none"> • Longitudinal; over a lifetime or as long as person is willing • Visits include: neurological exam, cognitive evaluation, informant interview and provide a blood sample for DNA at first visit. Follow-up visits every 18 months. Brain only autopsy paid for by study is available but not required to participate 	<p>Heather L. Prentice, B.S. 317-274-0561 or 800-526-2839 hlprenti@iupui.edu</p>

Who is needed	For which study	Length of study	Please contact...
<p>Persons with probable AD 50-90 years of age</p>	<p>Study includes Blood draws Electrocardiograms Vital Signs memory testing BMS-708163</p>	<p>30 weeks of participation Study volunteer with caregivers will need to complete 11 study visits</p>	<p>Lyla Christner, LPN 317-274-5029 or Julie Dickson 866-257-0195</p>
<p>African American family caregivers for persons w/AD-any stage Caregiver (spouse, adult child, other) Over 18 years old who has been the primary caregiver for at least 3 months</p>	<p>Anticipatory grief in African American caregivers</p>	<p>One Interview approximately 1 hour-long Interview will be recorded Complete a written questionnaire Compensation provided upon completion</p>	<p>Susan McLennon, RN, PhD 352-318-4409 (cell) or 317-278-0459 smcLennon@iupui.edu</p>
<p>Qualifying families with 2 or more living siblings diagnosed w/probable AD Plus a 3rd family member who is either >60 yrs of not affected or >50 yrs with memory problems</p>	<p>The Genetics of Late Onset Alzheimer's Disease (LOAD) Study</p>	<p>Longitudinal; over a lifetime or as long as person is willing Visits include: neurological exam, cognitive evaluation, informant interview and provide a blood sample for DNA at first visit. Follow-up visits every 18 months. Brain only autopsy paid for by study is available but not required to participate</p>	<p>Heather L. Prentice, B.S. 317-274-0561 or 800-526-2839 hlprenti@iupui.edu</p>
<p>Person's with probable AD, 50-85 years of age Has a caregiver that has contact w/patient at least 4 days per week</p>	<p>Infusion study of Octagam® 10% also known as an immunoglobulin</p>	<p>12 infusions at 2 -week intervals or 6 infusions at 4- week intervals Approximately 24 weeks Compensation provided for each completed visit, each completed lumbar puncture and PET scan</p>	<p>Julie Dickson, RN 1-866-257-0195</p>

The Indiana Alzheimer Disease Center Invites You to Attend Memory University 2010

Riley Outpatient Center Auditorium
601 West Drive, Indianapolis

The Indiana Alzheimer Disease Center and the Alzheimer's Association are presenting the 2nd Annual Memory University, a unique program for both professionals and families to learn more about Alzheimer's disease (AD) from nationally known clinicians working at the Indiana ADC. Participants will learn the most up-to-date information and will also be able to ask the experts the questions they have about AD and related disorders.

The series of four courses will be offered in consecutive weeks in June at the Riley Outpatient Center, Auditorium, 601 West Dr., Indianapolis. Registration will begin at 1 p.m. and the courses will run from 1:30 to 2:30 p.m. While we are offering this program free of charge, registration is required. Call 317-274-4939 or email rcludy@iupui.edu to register. Memory University 2010 will present:

Thursday June 3, 2010

Agitation, Delirium and Aggression in Alzheimer's, presented by **Malaz Boustani, MD**. Dr. Boustani is interested in enhancing the quality of the current health care system to accommodate the needs of patients with cognitive impairment in general and those with dementia in particular. He is one of the founding physicians of the Healthy Aging Brain Center, located within the Center for Senior Health at Wishard Health Services. Dr. Boustani is also the Chief Research Officer of the Indianapolis Discovery Network for Dementia (IDND), which is a network of health care providers, clinical researchers, and community advocates dedicated to enhancing the quality of life and care of individuals with dementia and their care partners.



Thursday June 10, 2010

When it's Not AD: Understanding Frontotemporal Dementia presented by **Brandy Matthews, MD**.



Dr. Matthews joined the Indiana Alzheimer Disease Center in 2008 as Associate Education Core leader and neurologist in the Clinical Core. After medical school in Indiana, Dr. Matthews completed her residency training at Mayo Clinic. She completed her fellowship training in Behavioral Neurology with a special interest in Frontotemporal Dementia at the University of California San Francisco. She is currently Assistant Professor of Clinical Neurology and Associate Director of the Neurology Residency training program at Indiana University. Her research interests include social cognition in neurodegenerative diseases and the intersection of neurology and the arts. She has recently played an active role on the planning committee for the 7th International Conference on Frontotemporal Dementia to be held in Indianapolis October 6-8, 2010.



Wednesday June 16, 2010 (Please Note: This is the only Wednesday date in the series)

Understanding Grief in Alzheimer Disease, presented by **Susan McLennon, PhD, APRN-BC**. Dr. McLennon is an assistant professor in the Department of Adult Health at Indiana University School of Nursing. Dr. McLennon completed her Bachelor of Science degree in Nursing from the University of Central Florida, Masters of Science in Nursing from the University of Florida, and doctorate from the University of Alabama at Birmingham. Dr. McLennon's research goals are directed towards improving the health of older adults with chronic illness. She is currently funded to investigate grief and loss in family

caregivers for persons with dementia. She has presented at national conferences and has published in several nursing and interdisciplinary peer-reviewed journals. Dr. McLennon is certified as a nurse practitioner in adult health and has clinical expertise with older adults.

Thursday June 24, 2010

Caring for the Late Stage AD Patient and Caregiver, presented by **Greg Sachs, MD FACP**. Dr. Sachs is the Chief of the Division of General Internal Medicine and Geriatrics, Department of Medicine, Professor of Medicine at Indiana University School of Medicine and faculty of the Indiana Alzheimer Disease Center. He also serves as a Research Scientist in the IU Center for Aging Research and the Regenstrief Institute. Dr. Sachs's research and writing focus on ethical issues in geriatrics, especially those involving people with dementia. Specific areas included in Dr. Sachs's work are the ethics of decision making for the care of people with dementia, palliative care in dementia, and the ethics of dementia research. He has published more than 80 articles in journals, with one of his recent notable papers being an editorial, "Dying from Dementia," which appeared in the October 15th, 2009 issue of *The New England Journal of Medicine*.



This program is offered free of charge but registration is required.

Please call 317.274.4939 or email rcludy@iupui.edu to register.

Persons with Dementia Make Recommendations for a Dignified Diagnosis

Adapted by Mary Guerriero Austrom, PhD

Alzheimer disease (AD) awareness is growing and persons with AD or other dementias are being diagnosed earlier than ever before. As a result, many people with these illnesses are able to tell us about their experience while living with AD and dementia. In 2008, the Alzheimer's Association published a statement written by people with dementia about their experiences. Called, *Voices of Alzheimer's disease: A summary report on the Nationwide Town Hall Meetings for People with Early Stage Dementia* it includes information on how people with dementia faced diagnostic challenges and were often dissatisfied with the medical community. As a result, the following guidelines were written based on their insights on how to make the diagnostic process better and how people with dementia would like to be included in discussions.

1. **Talk to me, the person with dementia, directly.** I am the person with the disease, and though my loved ones will also be affected, I am the person who needs to know first.
2. **Tell the truth.** Even if you don't have all the answers, be honest about what you do know and why you believe it to be so.
3. **Test early.** Helping me get an accurate diagnosis as soon as possible gives me more time to cope and live to my fullest potential and to get information about appropriate clinical trials.
4. **Take my concerns seriously, regardless of my age.** Age may be the biggest risk factor for Alzheimer's disease but AD is not a normal part of aging. Don't discount my concerns because I am old. At the same time, don't forget that AD can also affect people in their 40's, 50's and 60's.
5. **Deliver the news in plain but sensitive language.** This may be one of the most important things I ever hear. Please use language that I can understand and is sensitive to how this may make me feel.
6. **Coordinate with care providers.** I may be seeing more than one specialist—it is important that you talk to my other providers to ensure you all have the information so that changes can be identified early on and that I don't have to repeat any tests unnecessarily.
7. **Explain the purpose of different tests and what you hope to learn.** Testing can be very physically and emotionally challenging. It would help me to know the purpose of the test, how long it will take and what you expect to learn from it. I would also appreciate the option of breaks during longer tests and an opportunity to ask questions.

Continued on page 13

A Dignified Diagnosiscontinued from page 13

8. **Give me tools for living with this disease.** Please don't give me my diagnosis and then leave me alone to confront it. I need to know what will happen to me, and I need to know not only about medical treatment options but also what support is available through the Indiana Alzheimer's disease community.
9. **Work with me on a plan for healthy living.** Medications may help modify some of my neurological symptoms, but I am also interested in other recommendations for keeping myself as healthy as possible through diet, exercise and social engagement.
10. **Recognize that I am an individual and the way I experience this disease is unique.** This disease affects each person in a different way and at a different pace. Please be sensitive to this as you explain how this disease may change my life.
11. **Alzheimer's disease is a journey, not a destination.** Treatment doesn't end with the writing of a prescription. Please continue to be an advocate—not just for my medical care but also for my quality of life as I continue to live with AD.

Adapted from A Dignified Diagnosis Alzheimer's Association, 2009

2010 iADC Annual Scientific and Martin Family Caregiver Symposia

...continued from page 2

The theme for the 4th Annual Martin Family Symposium was *Ethics and Alzheimer Disease* and our speakers covered a variety of topics related to the theme.



Dr. Jason Karlawish from the University Pennsylvania gave a thought-provoking keynote on *Changing Concepts of AD*.



Dr. Alexia Torke from IU School of Medicine described her research on *Surrogate Decision-making*.



Dr. Kimberly Quaid from IU School of Medicine discussed ethical issues in *Diagnosis and Disclosure*.



Dr. Greg Sachs from IU School of Medicine presented important and *Sensitive Issues in Palliative Care in AD and Dementia*.



Chaplain Donna Pollard concluded the day with a talk on the *Role of the Chaplain in AD*.

Watch upcoming newsletters and emails for the dates for the iADC 2011 Symposia.

Save the Dates...Save the Dates...Save the Dates.....



Memory University 2010

June 3, June 10, June 16th, and June 24

Riley Outpatient Center Auditorium

For more information or to register call

call 317.274.4939

or

email rcludy@iupui.edu



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

or call

317- 274-7360

or

1-800-526-2839

7th International Conference on Frontotemporal Dementias Indianapolis Marriot Downtown

Wednesday October 6—Friday October 8, 2010

For more information contact:

Deb DeBusk

Conference Secretariat

635 Barnhill Drive, MS A143

Indianapolis, IN 46202

317.274.2106

ftd2010@iupui.edu

Registration is now open!



Reflections is published by the
Indiana Alzheimer Disease Center

EDITOR

Mary Guerriero Austrom, Ph.D.

CO-EDITORS

Bernardino Ghetti, M.D.

Hugh C. Hendrie, M.B., Ch.B.

Contributors in this issue:

ADEAR Center, National Institute on Aging

Alzheimer's Association

Mary Guerriero Austrom, Ph.D.

Martin R. Farlow, M.D.

Bernardino Ghetti, M.D.

Rhoda C. Ludy

EDITORIAL ASSISTANT

Rhoda C. Ludy

The editor welcomes your comments and letters

Indiana ADC Educational Core

IU Medical Center

1111 W. 10th Street, PB 305

Indianapolis, IN. 46202-4800

Indiana Alzheimer Disease Center Newsletter

Indiana University School of Medicine

Visit Our Website IADC.IUPUI.EDU

NONPROFIT.ORG

U.S. Postage

PAID

Indianapolis, IN

Permit No. 5677