

Reflections

iADC

Indiana Alzheimer Disease Center

NIA News: Long Term Care Facility Placement of Relative with Dementia Provides Little Emotional Relief for Caregivers

~Adapted from an article from the Alzheimer's Disease Education and Referral (ADEAR) Center at the National Institute on Aging

The results of a new study funded by the National Institute on Aging indicates that caregivers of dementia patients receive no relief from emotional burden when the decision is made to place a loved one suffering from dementia into long term care. The study showed that not only do these caregivers fail to experience relief from symptoms of depression and anxiety but that they actually tend to suffer more emotional trauma once they decide that nursing home placement is the best course of action.

This was the first systematic investigation of the emotional turmoil experienced by the caregivers during the transition of their loved one from home to long term care. The study, lasting 4 years, coordinated by the University of Pittsburg School of Medicine was led by Richard Schulz, PhD., the Director of the Center for Social and Urban Research at the University of Pittsburg. A number of relevant factors included the conditions that led to placement, the nature of the contact between the caregivers and their relatives after placement, and the effect of these factors on health outcomes among caregivers after placement.

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Faculty and staff are pictured in the atrium of the Medical Sciences building in front of artist Dale Chihuly's DNA Tower unveiled at IU School of Medicine on September 30, 2004. This artwork is an 18- to 19-foot sculpture that is symbolic of the spirit of the double helix.

***Best wishes for the holidays and 2005
from the faculty and staff of the
Indiana Alzheimer Disease Center***

Save the Dates:
I-CARE About AD Program
Teleconference
February 7, 2005
AD Community Conversations
See page 9 for more details.



Facility Placement Provides Little Emotional Relief...

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The study recruited 1,222 caregiver-patient pairs from six U.S. sites. Of the 180 caregivers who placed their loved ones in long-term care facilities, their symptoms of depression and anxiety remained as high as when they took care of these relatives at home. This is in contrast to the previous findings reported by Schulz and his group that showed that there was a significant improvement in depression following the death of a loved one after care-giving.

“Caregivers who place their loved ones in an institution do not get the sense of relief or experience the closure observed among caregivers whose loved ones pass away,” said Dr. Schulz. “They continue to feel distressed because of the suffering and decline of their loved one as well as having to face new challenges such as frequent trips to the long-term facility, reduced control over the care provided their relative, and taking on responsibilities such as coordinating and monitoring care,” he added.

According to Dr. Schulz, “cognitive and functional declines are common in patients who go into long-term care, and caregivers often blame themselves for this decline and question their decision to institutionalize their loved one.”

Approximately half of the caregivers in this study visited the patient on a daily basis and continued to help provide some form of physical care during their visits. It was a much more difficult transition for those caregivers who were married to the patient and those who visited the most frequently. The levels of depression reported were much higher for spouses than non-spouses both before and after placement. Levels of anxiety were reported as higher after placement for spouses.

The results of this study indicate that spouses, caregivers who continue to be involved, caregivers suffering from high levels of depression, and caregivers who do not have sufficient emotional support from others should receive interventions. “We need to help caregivers who place their relatives,” said Dr. Schulz. We need to treat their emotional distress, educate them about the nature of long-term care facilities and their impact on patient functioning, engage them in end-of-life planning, and prepare them for the eventual death of their loved one,” he added.

These findings are particularly relevant as Americans live longer and the number of families faced with placing loved ones into institutional care grows,” said Dr. Patricia A. Grady, Director of the National Institute of Nursing Research at NIH. “Knowing that these caregivers are vulnerable to ongoing depression and anxiety following such a placement, health professionals can make a difference in these people's well-being by helping them with their emotional distress, and by helping them prepare for and deal with these often difficult transitions,” Dr. Grady added. Results of the study indicated that clinical intervention, including treatment of anxiety and depression, may have significant benefits for caregivers, preparing them for the placement of their relatives.

These findings are very important for family caregivers who are thinking about long term care for their loved ones. Dr. Mary Guerriero Austrom, the Education Core Leader at the Indiana ADC, recommends that caregivers:

- ◆ *Have realistic expectations about long term care. Remember that it will take awhile for a patient to adjust to new living arrangements and noticeable decline is often seen after placement. Once a patient adjusts to the new routine, they do very well.*
- ◆ *Don't over-do the visiting; sometimes family caregivers feel guilty about placement and try to do too much at the nursing home. Take it easy and do not forget to take care of yourself. You cannot care for someone else if you don't take care of yourself first. Sometimes it is very difficult to visit with someone who can no longer communicate. Don't stop visiting; rather, schedule shorter visits; take someone with you so the two of you can talk to each other; read to the patient or play some favorite music.*
- ◆ *Talk to your doctor if you are feeling overwhelmed, anxious or depressed. Intervention for depression and anxiety can be especially helpful.*

The study appeared in the August 25, 2004 issue of the Journal of the American Medical Association (JAMA).

Helping a Loved One with Sensory Problems



Following are some suggestions which families have found helpful when their loved one suffers from sensory impairments, as well as AD.

If hearing is a problem:

-  Eliminate distractions or other sounds.
-  Turn off the TV or radio.
-  Close the door to the room.
-  Move to a quieter area.
- Face the listener and gain his/her attention before beginning to speak. If you lose eye contact, stop and try to get their attention again.
-  Do not chew gum or cover your face while talking.
-  Speak in a deeper (low pitch) voice– it will be easier to hear.
-  Speak slowly and clearly, but **do not shout**.
-  Use gestures to help the understanding of words.
-  Write information in bold printed letters to make sure the message is understood.
-  Speak to the ear with better hearing.
-  Ask questions to make sure the listener is following the conversation.

Good hearing is important for effective communication.

If vision is a problem:

-  Try a magnifier or high intensity lamps for reading or close up tasks.
-  Position needed items so they are in the field of vision.
-  Use a programmable telephone with large or raised numbers, or with photos of family members instead of numbers.
-  Keep the environment the same– do not rearrange items in the room.
-  Contact your local sight center for product and activity information.

If talking is a problem:

-  Ask questions that only require a yes/no, a nod or hand squeeze as a response.
-  Show you care by a gentle touch or a hug.
-  Bring someone along for the visit– he/she may enjoy listening to your conversation.
-  Talk about things that would be of interest to him/her.
-  Bring along a photo album and share some stories and memories.
-  Read to him/her about current events or topics of their interest from magazines, the newspaper or Bible.

Home Safety Issues for People with Dementia

~Mary Guerriero Austrom, Ph.D. and Lora A. Goudreau

There are a variety of home safety issues for those people with Alzheimer disease (AD) or any of the various forms of dementia. The reason for this is primarily due to the decline in cognitive abilities, specifically the abilities to reason and recall. For those who care for an elderly person with dementia, this is a continually growing concern. As the dementia progresses, the ability of the patient to live safely at home should be constantly evaluated as the needs for care increase. This is even more critical if the person with AD lives alone. The questions to regularly ask yourself are:



♦ **Can the person recognize a dangerous situation, such as a fire?**



♦ **Are there guns or knives in home which should be removed?**



♦ **Does the person know how to use the telephone in order to get help?**



♦ **Does the person seem to be content at home?**



♦ **Can the person take his/her own medications safely and correctly?**



♦ **Is the person showing signs of agitation, depression, or withdrawal?**



♦ **Does the person tend to wander?**



♦ **Is the level of confusion increasing?**



♦ **Does the person recognize familiar friends and family members when they arrive for a visit?**

If the answers to these questions seem to indicate a significant risk, it is probably time to consider increasing supervision in the home or alternative living arrangements to maximize safety and minimize the danger involved in living with dementia and living alone.

Since behaviors associated with AD and dementia are unpredictable, prevention is the most valuable tool in maintaining a safe home environment. Make adaptations in the home so that the danger is minimal while allowing the person to maintain as much independence as possible. This also tends to help minimize the level of agitation.

The tendency to wander is a serious risk for people with AD. While wandering, these patients often are unaware of temperature extremes, as well as many environmental dangers, such as moving vehicles. Unfortunately, it is difficult to predict who will wander and when this may take place. Clearly, not everyone with dementia engages in this type of behavior. However, it is the responsibility of the caregiver to establish security so that if or when this need arises it can be pursued safely. Please consider registering your loved one in Safe Return, a national registry for people with AD and dementia. Call your local Alzheimer's Association to learn more about this program.

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Following are suggestions for maintaining a safe home environment for people with AD and other dementing disorders.

In the kitchen:

- ⇒ **Unplug appliances; remove knobs from gas stoves**
- ⇒ **Insert plastic outlet covers**
- ⇒ **Restrict faucets with heavy rubber bands**
- ⇒ **Remove dangerous items such as knives, can openers, matches and chemicals**
- ⇒ **Install child safety locks on cabinets if necessary**

In the bathroom:

- ⇒ **Store medicine, razors, soaps and chemicals in one safe place**
- ⇒ **Color-code or label faucets “hot” and “cold”**
- ⇒ **Install grab bars, nonskid mats and shower chairs in the tub/shower area**
- ⇒ **Post reminders, such as “Flush Toilet” and “Exit”**

In the living and dining rooms:

- ⇒ **Simplify rooms by moving furniture if necessary and then keep it consistent**
- ⇒ **Remove light-weight furniture that moves easily and can cause falls**
- ⇒ **Eliminate obstacles such as cords, throw rugs and knick-knacks, especially fragile ones**
- ⇒ **Reduce clutter in the environment**

In halls and stairways:

- ⇒ **Install smoke alarms**
- ⇒ **Add nightlights to help light hallways and the bathroom**
- ⇒ **Darken some areas to deter wandering**
- ⇒ **Add color contrast to edges of stairs for step differentiation**

Doors:

- ⇒ **Install door alarms**
- ⇒ **Install locks in unusual positions such as very high or very low to prevent wandering outside**
- ⇒ **Painting the door the same color as the wall makes it less inviting**

These home modifications can help to safely prolong the time a person with dementia is able to remain at home. It is possible to successfully care for a loved one with dementia at home, as long as the necessary support and supervision are in place. At some point during the disease’s progression, however, the intensity of these requirements exceeds the abilities of most families. Serious consideration should be given to moving the person to a specialized long-term care facility when he or she requires around-the-clock care for such things as medication management or supervision for safety concerns. One of the most important responsibilities as a caregiver is to identify the point at which your loved one is no longer safe at home and make the appropriate decisions for their care.

Adapted from a recent article in Senior Link.

NIA and Industry Launch the Alzheimer's Disease Neuroimaging Initiative

~Reprinted with permission from the Alzheimer's Disease Education and Referral (ADEAR) Center at the National Institute on Aging.

The National Institute on Aging (NIA) in conjunction with other Federal agencies, private companies and organizations recently launched a \$60 million, 5-year public-private partnership called the Alzheimer's Disease Neuroimaging Initiative, to test whether serial magnetic resonance imaging (MRI), positron emission tomography (PET), other biological markers, and clinical and neuropsychological assessment can be combined to measure the progression of mild cognitive impairment (MCI) and early Alzheimer's disease (AD).

It is hoped that the study could help researchers and clinicians develop new treatments and monitor their effectiveness as well as lessen the time and cost of clinical trials. The project is the most comprehensive effort to date to find neuroimaging and other biomarkers for the cognitive changes associated with MCI and AD.

The NIA is joined in the partnership by the National Institute of Biomedical Imaging and Bioengineering (NIBIB) and by the Food and Drug Administration, all of which are part of the U.S. Department of Health and Human Services. The Foundation for NIH is managing corporate and private participation, and has received commitments totaling more than \$20 million in contributions from the following companies and organizations: Pfizer Inc, Wyeth Research, Eli Lilly and Company, Merck & Co., Inc., GlaxoSmithKline, AstraZeneca AB, Novartis Pharmaceuticals Corporation, Eisai Global Clinical Development, Elan Corporation, the Institute for the Study of Aging (ISOA), and the Alzheimer's Association.

About two-thirds of the funding is expected to come from federal agencies while private partners are expected to make up the other third. Additional studies will be funded by other NIH grants. "This is an extraordinary pooling of talent and resources toward a common goal -- delaying or preventing Alzheimer's disease," said Richard J. Hodes, M.D., Director of the NIA. "The initiative should become a landmark study in the development of neuroimaging and other biomarkers, helping us to find biological changes early so that we can identify the people at highest risk of the disease and test the effectiveness of new therapies more quickly and efficiently."

The study will take place at approximately 50 sites across the U.S. and Canada. In April 2005, investigators will begin recruiting about 800 adults, aged 55 to 90 years, to participate in the research. This will include approximately 200 cognitively normal older individuals to be followed for 3 years, 400 people with MCI to be followed for 3 years, and 200 people with early AD to be followed for 2 years.

The study will compare neuroimaging, biological, and clinical information from these participants, looking for correlations among the data that will track the progression of memory loss from its earliest stages. Neuroimaging research has suggested that PET or MRI may serve as a more sensitive and consistent measure of disease progression than the neuropsychological and cognitive assessments now typically used in research and clinical practice. As MCI and AD progress, for example, areas of the

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Alzheimer's Neuroimaging Initiative

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brain involved with memory, such as the hippocampus (a part of the brain heavily involved in memory), shrink. Using the high resolution images produced by MRI, researchers will evaluate the best ways of measuring the volume loss in the hippocampus and other brain structures. PET scans assess measuring the rate of metabolism of glucose, the brain's fuel. PET scans of people with AD show that glucose in certain parts of the brain is metabolized at lower levels than in healthy people, and previous studies have shown that low glucose metabolism can be seen in some people even before noticeable symptoms of memory loss occur. The Initiative will seek to identify additional biological factors from blood, cerebrospinal fluid (CSF), and urine samples.

"The key challenge here is to identify critical markers that respond to treatments aimed at slowing the progression of mild cognitive impairment and Alzheimer's disease," says Michael W. Weiner, M.D., the study's Principal Investigator. "For example, today, imaging is used to rule out other causes of memory problems, still not leaving the researcher or the clinician with a very clear idea of what is going on. By the end of this study, we should be able to use imaging and other biomarkers to accurately monitor disease progression and detect the effects of treatments which can slow that progression."

Information about the participating research sites and co-investigators leading various aspects of research may be obtained from the NIA. While recruitment for the study will not begin until spring 2005, people interested in participating in this study can contact the NIA's Alzheimer's Disease Education and Referral Center (ADEAR) at 1-800-438-4380 or can go to <http://www.alzheimers.org/nianews/nianews70.html> for additional information and a list of sites.

The NIA leads the federal effort in research on AD and age-related cognitive change. The NIA is currently funding 6 prevention trials and 19 treatment trials for AD, in addition to this Neuroimaging Initiative. For more information on participation in an AD clinical study, visit <http://clinicaltrials.gov> (search for "Alzheimer's disease" trials), or visit the ADEAR Center website at <http://www.alzheimers.org/trials>. Several of the clinical trials are being conducted locally, see pages 10 and 11 in this newsletter for more details.

Dr. Martin Farlow, Clinical Core Leader and Professor of Neurology at IU School of Medicine explains that researchers will be following normal older adults, persons with mild cognitive impairment and AD patients for this new initiative. "We are looking to identify the earliest signs of AD before well recognized symptoms are present. The eventual goal of this is to enable clinical trials of medications that can treat cognitive impairment at the earliest possible stages where it may be more responsive and can provide increased benefits with the greatest possibility of preventing the development of long term disability in patients and families." The Indiana ADC will be one of the 50 sites in this exciting initiative. Look for more information in future newsletters.

In Memory...

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

In Memory of Eleanor Orrick

Dr. J. David Smith
Mr. & Mrs. Gregory D. Sager
Ms. Kim M. Gattle
Dr. & Mrs. Louis B. Cantor
Mr. Samuel J. Sample
Mr. Jayson G. Cooley

***In Memory of John P.
McGovern***

Mr. Walt Edwards
Ms. Jacquelyn A. McGovern

In Memory of Mae Ripberger

Mr. Richard V. Erk
Ms. Veda Sparks

In Memory of Odell Gray

Eli Lilly and Company

In Memory of Anita Metzler

Ms. Virginia A. Smith

Benevolent Contributions

Johnson-Weaver Foundation

In honor of your loved one, please consider a donation in their name.

Your contributions are gratefully accepted and are used to further research and education in the area of Alzheimer disease. Please make checks payable to: IU Foundation/Alzheimer Research. Forward to: 541 Clinical Dr. CL 590, Indiana University, Indianapolis, IN. 46202-5111. Donations to this fund are a wonderful way to remember or honor a loved one. Contributions are tax deductible. Call 317-274-4939 for information on making a bequest or a planned gift to this fund.



Members of the IADC attended and supported Chocolate Sunday, an annual fundraiser to support the Alzheimer's Association of Greater Indiana. Pictured from left to right are: Dr. and Mrs. Bernardino Ghetti, Dr. Eric Boez, Dr. Tatiana Faroud, Dr. and Mrs. Martin Farlow, Drs. Hugh Hendrie, and Dr. and Mrs. Mike Conneally. Dr. Mary Guerriero Austrom, Education Core Leader, served as chair for the event.

Upcoming Events

Alzheimer's Disease Community Conversations

***Glendale Branch Library
6101 N. Keystone Ave. Indianapolis, IN 46220***

“Alzheimer’s Disease: Community Conversations” provides an opportunity for continuing education and discussion for those interested in Alzheimer’s disease. Speakers will explore the human toll that the disease takes on patients and caregivers and will offer practical, up-to-date information and suggestions for those impacted by the disease. Each evening, presentations by knowledgeable speakers will be followed by the opportunity for candid discussion.

Thursday, March 10, 2005: Chicken Soup for the Caregiver’s Soul

*Come listen, laugh, and cry with LeAnn Thieman, nationally recognized speaker, author, and nurse. LeAnn will inspire you to balance your life, live your priorities, and make a difference in the world.
Location: Meridian Methodist Church, 5500 N. Meridian St. Indianapolis, IN*

Wednesday, April 13, 2005: Healthy Caregiving

Discuss the importance of and means to keeping the caregiver healthy– in body, mind, and spirit.

Thursday, May 12, 2005: Keeping the Love Alive

Examine the transitions involved in a relationship with someone with Alzheimer’s disease.

Thursday, June 9, 2005: What About Long-Term Care?

Investigate the options available for institutional care, including how to select a facility.

I-CARE about AD Project

Teleconference February 7, 2005 6:30-8:30 pm
An Overview of Mild Cognitive Impairment and Dementia
Speaker - Fred Unverzagt, Ph.D.



Learn about very mild changes in thinking and cognition and what it means. Call from your home and listen to the program.

For more information or to register, call the IADC Education Core at (317) 274-4939.

Participants Needed for AD Research

(Continued on page 13)

Dr. Martin Farlow and his colleagues at the Indiana University School of Medicine are working to find new treatments to delay or prevent AD and need your help. The **AMEND** study is looking for participants with AD. The primary purpose of this study is to establish the safety and effectiveness of a study medication after 12 months of treatment in patients with AD.

We are looking for volunteers who:

- Are between 50–90 years of age
- Have been diagnosed with AD
- Have a caregiver who can provide information and attend all 11 clinic visits

Depending on your qualifications, the study involves:

- 1 study visits to the hospital over 1 year
- Compensation of \$50.00 per study visit
- Free exams and testing required by this study
- Free study medication

Does your loved one have Alzheimer’s Disease or memory problems? Do they have any of the following symptoms?

- ♦ Memory loss?
- ♦ Misplacing things?
- ♦ Changes in personality?
- ♦ Problems with language?
- ♦ Poor or decreased judgment?
- ♦ Disorientation to time and place?
- ♦ Difficulty performing familiar tasks?



For more information on either of these two studies please contact Scott Herring at (317) 274-9903, or via email at sherring@iupui.edu.

If you said yes to any of these symptoms and your loved one is at least 50 years old, they may be eligible to participate in a research study being conducted by Indiana University Medical School faculty involving an approved AD medication. Qualified participants will receive an assessment and study medication at no cost, and will also have their transportation costs paid for.

Can Cholesterol-Lowering Drugs Help Slow Alzheimer’s Disease?

Cholesterol-lowering drugs, called “statins,” are effective weapons in the fight against heart disease. Some evidence suggests that statins may also be able to slow the devastating effects of AD on the brain. The Alzheimer’s Disease Cooperative Study, a group of research centers sponsored by the National Institute on Aging, is launching **CLASP** (Cholesterol Lowering Agent to Slow Progression of Alzheimer’s Disease), a research study to find out more about the effect of one statin, called simvastatin (Zocor) on AD.

The CLASP study is seeking volunteers who:

- *Have mild to moderate AD*
- *Are aged 50 or older*
- *Speak English*
- *Do not currently take or need cholesterol-lowering drugs*
- *Have a study partner—a friend or relative who can accompany the volunteer to all clinic visits and answer questions about him/her.*

CLASP is a randomized, placebo-controlled research study. Half of the participants will be assigned at random to receive simvastatin, the other half will receive a placebo or inactive pill. Participants will be assessed regularly by physicians and qualified health care professionals during the 2-year study.

For more information, or to volunteer for this study, call Martha Mendez, R.N. at (317) 278-9773.

Can a drug prevent or reduce difficult behaviors in Alzheimer's disease?

The VALID Study (VALproate In Dementia)

Previous research has shown that *Valproate*, an anticonvulsant drug, may be helpful in slowing AD and some of its symptoms. The VALID study will test whether Valproate is effective in delaying, reducing, or preventing difficult behaviors in people with early stage AD, and whether it has any effect on slowing the progression of AD itself.

VALID is sponsored by the Alzheimer's Disease Cooperative Study [ADCS] based at the University of California, San Diego and funded by the National Institute on Aging.

The VALID Study is seeking participants at 30 sites nationwide.

Researchers for this study are looking for participants who:

- are **between 55 and 90 years old**,
- have been **diagnosed with probable AD**, and
- have **NOT experienced agitation or psychosis** since the onset of AD.

Participants must also have a **study partner** who can provide informed consent to participate and is willing and able to attend all clinic visits to report on the study participant's activities and behavior. Participants will be assigned at random to receive Valproate or a placebo (inactive pill), and will be regularly monitored during the 26-month research study by physicians and qualified health care professionals who specialize in dementia.

**For more
information on
either of these studies
please contact
Martha Mendez, R.N.
at
(317) 278-9773, or via
email at
mwmendez@iupui.edu.**

You can be a VITAL part of the effort to slow Alzheimer's disease:

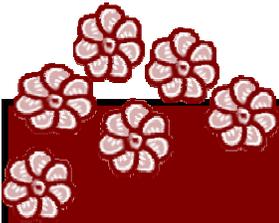
A new nationwide research study—**VITAL (Vitamins to slow Alzheimer's disease)** is recruiting 400 volunteers to test whether taking high-dose supplements of vitamins B6, B12, and folate will slow the progression of AD. People with AD have elevated levels of homocysteine ("ho-mo-SIS-teen") in their blood. Homocysteine is an amino acid that is produced in the human body. High-dose supplements of folate and vitamins B6 and B12 can lower homocysteine levels. Researchers will investigate whether a regimen of these vitamins might also stall the devastating effects of AD.

VITAL is also sponsored by the ADCS.

The VITAL study needs volunteers who:

- ◆ **have mild to moderate AD**
- ◆ **are 55 years old or older**
- ◆ **are fluent in English**
- ◆ **are on stable medications for at least 4 weeks prior to screening visit**
- ◆ **have a study partner—a friend or relative who can accompany the volunteer to all clinic visits and answer questions about him/her.**

VITAL is a randomized, placebo-controlled research study, including two groups of unequal size: 60% of the participants will be assigned at random to receive daily high-dose supplements and 40% will receive identical placebo or inactive pills. Participants will be assessed regularly by physicians and qualified health care professionals during the 18-month study.



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.

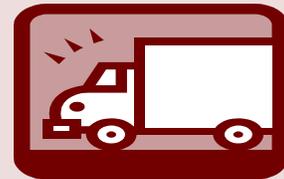
Please contact the National Cell Repository for Alzheimer Disease (NCRAD) to learn more about this research opportunity.

E-mail NCRAD at alzstudy@iupui.edu
or call
317- 274-7360
or

INDIANA ALZHEIMER DISEASE CENTER NEWSLETTER
INDIANA UNIVERSITY SCHOOL OF MEDICINE
VISIT OUR WEBSITE
WWW.IADC.IUPUI.EDU/

FYI

On December 1, 2004 the IADC Clinical Core and the Alzheimer's Research Clinic were moved to the Mark Dyken Neurology Clinic, Room 1710 of University Hospital. Thank you for your patience while relocating our programs.



The following phone numbers remain the same:

Neurology Call Center: (317) 278-5450
Toll Free: (866) 740-1941

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