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ndiana Alzheimer Disease Center

Dr. Ghetti, IADC Director, Receives Lifetime Achievement Award

Mary Guerriero Austrom, PhD



Bernardino Ghetti, M.D., has been honored by the Alzheimer's Association with the Henry M. Wisniewski Lifetime Achievement Award in Alzheimer's Disease Research. The award was presented July 27, 2008 during the International Conference on Alzheimer's Disease in Chicago.

Dr. Ghetti has spent the past 40 years studying the pathology and the biochemical and molecular mechanisms of dementias. A Distinguished Professor and Chancellor's Professor at Indiana University School of Medicine, Dr. Ghetti is

Director of the Indiana Alzheimer Disease Center at IU School of Medicine and Co-Director of the Division of Neuropathology. A professor of pathology, psychiatry, medical and molecular genetics, and neurology, he has been on the IU faculty since 1976.

Dr. Ghetti and his colleagues have contributed to the understanding of how certain genes and mutations in those genes can lead to various types of dementia, including those types that manifest early in adult life. Since the discovery of a mutation in the APP gene in 1991, Dr. Ghetti and his colleagues have investigated numerous familial forms of Alzheimer disease (AD) and clarified the nature of the amyloid protein that accumulates in the plagues. Between 1993 and 1998 he led an international research team that identified new form of autosomal dominant frontotemporal dementia, called multiple system tauopathy with presenile dementia. This type of dementia first appears in individuals in their 40s and 50s and is both pathologically and clinically different from AD.

Dr. Ghetti's work also has been seminal in understanding the protein that makes the neurofibrillary tangles believed to be a cause for the onset of many dementing illnesses. For the past 25 years, he has also made significant contributions to the understanding of Gerstmann-Sträussler-Scheinker disease, a prion disease, that begins with ataxia and, similar to AD, is chronic and leads to dementia.

Dr. Ghetti received his medical degree at the University of Pisa, Italy, and completed postdoctoral fellowships at the University of Pisa and Naples, Italy, and Albert Einstein College of Medicine in New York.

In 1999, Dr. Ghetti was awarded the Potamkin Prize for Research in Alzheimer and Pick Disease by the American Academy of Neurology for his work in the discovery and identification of frontotemporal dementias. In 2005, he received an honorary doctorate from the University of Siena, Italy. Dr. Ghetti is President of the International Society of Neuropathology, 2006-2010. The Henry Wisniewski Life-Time Achievement Award is particularly significant to Dr. Ghetti, since Dr. Wisniewski was his mentor at the Albert Einstein College of Medicine.

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Older Adults With Mild Memory Impairment Can Benefit From Cognitive Training in Areas Not Dependant on Memorization

Mary Guerriero Austrom, PhD

Dr. Frederick W. Unverzagt, Associate Director of the Indiana Alzheimer Disease (IADC) Clinical Core and Professor in the Department of Psychiatry published a very important paper about his research on cognitive skills and older adults.

"Our previously published studies have found that the ACTIVE protocols improve the function of older adults in certain target skills of cognitive training," said Dr. Unverzagt. "These skills -- memory, reasoning, and speed-of-processing -- were emphasized because they are thought to be important in allowing elders to maintain independent living. The current study builds on the previous findings by focusing on those adults who already have



experienced some loss of memory." Older adults with pre-existing mild memory impairment benefit as much as those with normal memory function from certain forms of cognitive training that don't rely on memorization, according to a study published in the *Journal of the International Neuropsychological Society*. These findings could indicate the ability for older adults to maintain skills that allow them to carry out daily tasks and lead a higher quality of life as they age.

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In the study supported by the National Institutes of Health (NIH), older adults who were otherwise healthy and living independently received training focused on targeted cognitive skills. A small number of participants in the study were found to have a decline in their ability to form new memories of experiences or facts, an ability called declarative memory. These individuals were unable to improve their memorization skills, but were able to improve their reasoning skills and become faster at processing visual information.

"Research such as this is critical to discovering ways to help older individuals stay independent and take charge of their own lives and health for many years to come," said Patricia A. Grady, Ph.D., RN. Director of the National Institute for Nursing Research (NINR) at the NIH. "Persons with mild memory impairment may have difficulty improving in this one area, but may still benefit from different types of learning and mental activities to improve their quality of life and functioning -- a major goal of the NINR mission."

"The notion that interventions can be designed and demonstrated to maintain cognitive skills with age is of enormous interest in the research community right now," Richard J. Hodes, M.D. Director of the National Institute for Aging (NIA) "This study tests that hypothesis and shows the potential promise of continued research in this area."

In the study participants were divided into treatment groups to receive cognitive training in one of three target skills. The memory training focused on methods to learn and remember new information such as: using word lists and short narratives.

The reasoning training emphasized pattern detection and inductive skills to solve problems. The speed-of-processing training addressed the speed of responses to visual and manual prompts on a computer screen. Only the memory training component relied on the participant's declarative memory ability. Training was conducted in 10 sessions of 60-75 minutes over a period of 5-6 weeks.

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Older Adults With Mild Memory Impairment

(continued from page 2)

The control group received no training, participants who received the memory training and had normal memory ability at the start of the study showed significant improvement in memorization skills. However, among the participants with declines in memory function, those in the memory training group showed no benefit, while those who received the reasoning or the speed-of-processing training showed skills. improvement in these areas comparable to normal-memory participants.

According to, Dr. Unverzagt the next step for this research would be to "examine the effect of other cognitive subgroups (low reasoning, low speed-of-processing) on trainability.

Paper Unraveling the Natural History of Inherited Frontotemporal Dementia in One of the Largest Known Families Worldwide Published

Salvatore Spina, MD

Our recent paper in *Brain* describes the natural history of inherited frontotemporal dementia in one of the oldest and largest known families with the disease associated with a mutation in the *Tau* gene. The *Tau* gene encodes for a protein that plays an important role in the functioning of neurons in the brain. *Tau* mutations lead to the pathological accumulation of tau protein in the brain of affected individuals, which is responsible for progressive brain degeneration, and ultimately to the development of symptoms such as personality changes, loss of cognitive skills and dementia. The paper explores the evolution of clinical symptoms in a large number of affected individuals from the Multiple System Tauopathy with Presenile Dementia (MSTD) family, and compares clinical findings, neuropsychological data, genetic characteristics, and data obtained with magnetic resonance imaging (MRI) to the anatomical changes observed in the brain of patients at autopsy.

This study has unraveled the existence of a newly identified clinical presentation of the disease in this family, represented by movement disorders resembling those of a sporadic disease known as progressive supranuclear palsy. In addition, we have been able to identify the association of specific genetic variants, beyond the mutation in the *Tau* gene with specific symptoms and signs of disease presentation. Finally, we have shown that the rate of the progressive reduction of brain volume in affected individuals, as assessed by MRI, can provide relevant information on the severity of the disease course. Interestingly, the rate of the progressive reduction of brain volume in pre-symptomatic individuals, carriers of the mutation in the *Tau* gene who have not yet manifested symptoms of the disease, has been shown to be a reliable marker for assessing the disease progression.

These new data have a tremendous impact on the counseling of individuals affected with this particular form of inherited frontotemporal dementia. They also contribute to the understanding of the natural history of the disease and the evolution of its clinical and anatomical changes. More importantly, they suggest the possibility that, in the near future, genetic and neuroimaging markers may be used in order to predict the disease onset before the appearance of clinical symptoms, and therefore act with specific therapeutic approaches before the occurrence of the unredeemable anatomical and functional deficits.

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Pai	Participants Needed for AD Research	or AD Research	
Who is needed?	For which study?	Length of study?	Please contact
AD, MCI, Lewy body disease, frontotemporal dementia, mixed dementia, vascular dementia, or Parkinson's dementia	 Registry of volunteers for various current and future studies 	 Will vary by study. Compensation for time and travel may be provided. Specific details will be provided before enrollment. 	Julie Dickson, RN 317-278-4333 or 866-257-0195
Persons diagnosed with probable AD, MCI, or cognitively healthy elderly with or without significant subjective cognitive complaints	• Study designed to examine changes in sentence comprehension in these populations.	• 1 90-minute session. Compensation for time and travel provided.	Vanessa Taler, PhD 812-856-2603 or 812-330-1529
 Women diagnosed with probable AD Post-menopausal 60 years old + Currently taking medication to treat AD 	• Study of the effects of Ralozifene (Evista) on the symptoms of AD in postmenopausal women.	• 4 times per year (once every three months)	Sheryl Lynch, LPN 317-278-8307 or 866-257-0195
 Diagnosis of probable AD 45 – 90 years of age Currently taking Aricept Has a primary caregiver willing to participate as well. 	• Clinical trial to compare 23mg <i>Donepezil</i> sustained release (an investigational form of the drug) to 10mg <i>Donepezil</i> (Aricept).	 7 times in 24 weeks procedures and exams provided at no cost. Compensation for time and travel provided 	Sheryl Lynch, LPN 317-278-8307 or 866-257-0195
 Persons diagnosed with probable AD. 50 years old + Has a caregiver or study partner with them 3 days per week. Willing to travel to IU Medical Center. 	• Clinical trial for compound <i>PF-04494700</i> to test if it is able to change the rate of cognitive decline and effect biomarkers in persons with AD.	 12 visits or 25 months. Study medication, procedures and exams provided at no cost. 	Sheryl Lynch, LPN 317-278-8307 or 866-257-0195

 Persons diagnosed with frontotemporal or semantic dementia. 40 – 80 years old 	• Clinical trial to determine whether <i>memantine</i> is effective in slowing decline in frontotemporal dementia.	 6 visits and 2 phone calls over 8 months. Compensation for time and travel provided. 	Julie Dickson, RN 317-278-4333 or 866-257-0195
 Persons diagnosed with probable AD. 55 years old + 	 Phase 3 clinical placebo- controlled trial to test the safety and effectiveness of LY4560139 in AD. Placebo group will get study medication as well. 	 20 visits over 22 months. Medication, procedures and exams provided at no cost. Compensation for time and travel provided. 	Elva Van Hook, RN 317-278-8389 or 866-257-0195
 Persons diagnosed with probable AD. 50-88 years old Caregiver will to participate. 	• Clinical trial to assess the safety and effectiveness bapineuzumab in AD using infusion.	 20 visits over 18 months that include 6 infusions (1 every 13 weeks). Compensation for travel provided. 	Elva Van Hook, RN 317-278-8389 or 866-257-0195
 Persons diagnosed with probable AD. 50 – 85 years old 	• Clinical trial to assess the safety and effectiveness of <i>ELND005</i> in AD.	 16 visits over 18 months. Medication, procedures and exams provided at no cost. Compensation for travel provided. 	Scott Herring, RN 317-274-9903 or 866-257-0195
 Healthy older adults 75 years + Living at home. 	Home-based assessment study.Must take a multi-vitamin (provided)	 4-year study with variable assessment methods. Schedule of visits will be discussed with you. Annual compensation provided. 	Elva Van Hook, RN 317-278-8389 or 866-257-0195
 Healthy older adults 60 – 90 years old Right-handed Completed at least the 10th grade of education 	 Study of memory in healthy older adults Participants will complete questionnaires, receive neuropsychological exams, a blood draw and a brain scan. 	 3-year study with 3 assessments 18-months apart. Each visit will take 5-6 hours and can be schedules over 2 days. Compensation for time and effort provided. 	Dr. Alette Wessels 317-274-6633 awessels@iupui.edu



Caregiving Tips for Early Alzheimer Disease Care

Mary Guerriero Austrom, PhD

In the early stages of Alzheimer disease (AD) a person may be able to perform the daily tasks that allow them to live and function independently. Unfortunately, as the disease progresses, the person's ability to function independently will also decrease. Anticipating changes in one's abilities and making some adjustments to the environment and routine can help them maintain function and some independence. A key goal of care should be to keep the person with AD as independent and functional as possible for as long as possible. Caregivers often do too much for the person too soon. A person with AD may react with frustration and even aggression when daily task become difficult or challenging. To reduce these challenges and ease frustrations try using the following tips.

- Establish and maintain a predictable routine. Try to respect the person's preferences. For example, if they always had their bath in the evening, do not insist that they bathe in the morning.
- Reduce distractions especially during dressing, bathing or mealtimes to help them stay focused on the task at hand.
- Schedule the hardest or the most time-consuming tasks such as bathing, dressing, appointments, at the time of day when the person is most calm and agreeable (often in the morning).
- Engage the person with AD in daily tasks as much as possible. Everyone, with AD or without, needs to feel needed. Thus, having them sort the silverware, fold laundry, rake leaves, sweep the garage, or vacuum can make them feel valued and important. contributions to the family.
- Relax your standards; allow them to do as much as possible with the least amount of assistance. Don't always strive to do things the way they have always been done. Take, for example bathing, it may not be necessary to bath everyday, a sponge bath or shower may work better. Consider using soaps, shampoos and toothpaste that do not need to be rinsed to make the task easier.
- Limit choices when decision making becomes difficult. For example, instead of asking "What would you like for dinner tonight?" which is open-ended, ask "Would you like chicken or fish for dinner tonight?" Instead of directing them to get dressed, hold up two shirts and ask which one they would like to wear today.
- Expect things to take longer than they used to. Schedule more time to complete even simple tasks so that neither of you feel rushed.
- Provide instructions one step at a time and keep instructions simple and straightforward. Try to avoid phrases like "just hop on up here" or "jump right in" as the person may interpret them literally.

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Caregiving Tips for Early AD Care

(Continued from page 6)

- Be flexible and adapt your routine as needed over time because the person's ability to function and cope will decline over time.
- A person with AD may insist on wearing the same outfit everyday. If that happens consider buying a few identical outfits. When your loved one is bathing, simply switch the worn outfit for a clean one.
- To reduce the risk of choking, thicken drinks with gelatin or cornstarch. A person may be more prone to choking as AD progresses. Get training on using the Heimlich maneuver.

Create a safe and supportive environment

- Every home should have a first-aid kit, a fire extinguisher and working smoke alarms. If the person with AD is a smoker never allow them to smoke alone. Control access to matches and lighters.
- AD impairs judgment and problem-solving skills, increasing your loved one's risk of injury. Modifying the home to help them maneuver safely will prevent injuries later.
 - Avoid throw rugs, extension cords and any clutter that could cause them to trip
 or fall
 - Install handrails in critical areas to prevent falls, especially in the bath and along stairwells.
 - Install locks on cabinets that contain medicine, alcohol, guns, toxic cleaning products, and dangerous tools. Better still, remove guns and dangerous items from the home.
- Remove electrical appliances from the bathroom to avoid the risk of electric shock.
- Set the water-heater temperature no higher that 120 F (49C) to prevent burns.
- At some point, the person with AD should not be driving the car. Discuss this with their physician and help and help the person prepare for this change.
- Enroll in MedicAlert Alzheimer's Association Safe Return program; a 24-hour nationwide emergency response service for individuals with Dementia. The enrollment phone number is 1-888-572-8566.

Every person with AD experiences the disease differently. Remember that patience, flexibility and planning ahead can alleviate your frustrations and that of the person with AD. You do not have to experience this alone. The Alzheimer's Association provides many community services designed to help both the caregiver and the person with AD. Call 1-800-272-3900 for more information about services in your area.

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In Memory....

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

from January 1, 2008 to present

In Memory of Don E. Dilley: Peggy L. & Donald D. Siller

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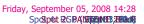
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Call (317) 278-8480 for information on making a bequest or planned giving to this fund.



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Recommended Reading for the Caregiver

We have compiled a list of new books related to Alzheimer disease, dementia, and caregiving information. We hope they help enlighten you or help you in some way. If you have read a book that you would like to share, please let us know by calling: *The IADC Education Core at 317-274-4939 or emailing us at iadc@iupui.edu. Most books are available at your local library.*

Cost

Roxana Robinson Farrar, Straus & Giroux © 2008

Middle aged woman, sandwich generation. Parent and adult child challenged by Alzheimer's disease.

Mothering Mother Carol D. O'Dell Kunati © 2007

A caregiving daughter's humorous and heartbreaking memoir of her mother's ordeal with Alzheimer's disease.

Alzheimer's Care with Dignity Frank Fuerst F. Fuerst © 2007

"The must have handbook to help you care for your loved one at home with dignity and respect."

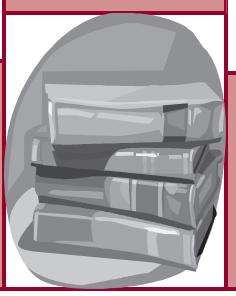
Can't Remember What I Forgot: Good News From the Front Lines of Memory Research

Sue Halpern Harmony Books © 2008

World of memory research with latest findings about memory loss.

For additional information Check out these websites:

www.adear.org www.alz.org www.imclp.org



Grandfather's StoryCloth Linda Gerdner

Walnut Creek, CA: Shen's Books © 2008

Ten-year old Chersheng helps his garandfather cope with his failing memory brought on by Alzheimer's Disease.

Still My Grandma

Veronique van den Abeele, & Claude K. Dubouis

Eerdsmans books for Young

Readers © 2007

A young girl describes her special relationship with her grandmother, both before and after Grandma developes
Alzheimer's Disease.

The Foursome

Ceyla Bowers Genesis Press, Inc © 2007

African American love story examination of relationship and effects of Alzheimer disease.

The Indiana ADC does not endorse any particular book; we are simply sharing information which may be helpful.

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IADC 2008 Conference on AD



INDIANA ALZHEIMER DISEASE CENTER PRESENTED

SYMPOSIA ON MILD COGNITIVE MPAIRMENT "AN EVOLVILNG CONCEPT IN RESEARCH And CLINICAL PRACTICE"

AND

THE SECOND ANNUAL
MARTIN FAMILY
ALZHEIMER DISEASE
SYMPOSIUM
MILD COGNITIVE
IMPAIRMENT:
"IMPACT ON THE
PATIENT AND FAMILY"

Pictured above from (l to r)

1st row: Drs. Andrew J. Saykin, Ronald C. Petersen, Yvonne Lu, Bernardino Ghetti, Christopher M. Callahan, and M.-Marsel Mesulam.

Second Row: Drs. John Ringman, Mary Guerriero Austrom and Bruce L. Miller.

Third Row: Drs. Martin Farlow and Frederick Unverzagt.

The IADC hosted a two-day symposium on mild cognitive impairment. On Friday, April 18th, 2008, event featured several visiting faculty as well as the IADC's own faculty. They highlighted current concepts in the diagnosis, genetics, imaging and therapy associated with mild cognitive impairment (MCI). Program participants learned about the current criteria for the diagnosis of MCI, and how to recognize the first symptoms and signs of frontal lobe dysfunction.

On Saturday, April 19th, 2008, Dr. Ronald Petersen of the Mayo Clinic delivered the keynote address at the Second Annual Martin Family Alzheimer Disease Symposium. Speakers provided information about research in the area of MCI, as well as current best practice approaches to the management of MCI and intervention strategies for helping patients and family members cope over time.

The participants learned how neuroimaging can identify brain regions showing early structural and functional changes. They also learned about recent MCI therapeutic studies and interventions that may improve and/or maintain cognitive function. Finally, participants were able to appreciate how the person with MCI feels about the diagnosis and how their caregivers can provide support at home and in the community.

The MCI Symposia had a record number of participants on both days. Attendees commented on the powerful and relevant material covered in the symposia. The IADC Spring 2009 Conference is being planned.

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Keeping Persons with Alzheimer Disease Active



People with Alzheimer's disease (AD) should keep busy, both mentally and physically. While this can be challenging it can be also fun. The National Institute on Aging reminds us that building on current skills works better than trying to learn something new if someone has a diagnosis of AD. Here are some suggestions to keep persons with AD active:

- Keep activities simple and at the person's current level or ability.
- Offer support as needed, and break the activity into small steps.
- Don't push any activity if you notice the person getting agitated.
- If the person enjoys certain activities, try to make them part of the daily routine.
- Have the person assist in daily routines. At mealtime, for instance, have them help set the table, prepare the food and clean up afterwards.
- If there is a garden let them help plant, weed and water plants.
- Rake leaves in the fall.

Staying busy helps build self worth and including the person with AD in activities helps to stave off feelings of loneliness.



The Alzheimer's Association's Annual Memory Walk

The Indiana Alzheimer Disease Center Team will participate in the local Memory Walk.

If you would like to join our team or make a donation you can do so online at:

www.alz.org/indiana and search for The page for the Indiana Alzheimer Disease Center Team or call 1-800-272-3900

> Memory Walk will be held Sunday October 19, 2008 at the Indiana State Fairgrounds in Indianapolis. Event day Registration at 12:30 pm We hope you can join us.



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



IADC

Spring 2009 Conference
Look for an announcement for the
Third Annual Martin Family
Alzheimer Disease Symposium
Date will be announced soon!



Call 317-274-4939 or email rcludy@iupui.edu for more information

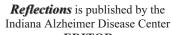


Is Alzheimer Disease in your family photo?

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 call 1-800-526-2839.



EDITOR

Mary Guerriero Austrom, Ph.D.

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Bernardino Ghetti, M.D. Hugh C. Hendrie, M.B., Ch.B.

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The editor welcomes your comments and letters

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