

Emory University School of Medicine Alzheimer's Disease Research Center

Research Volunteers Get Results

On October 24, 2008 over a 100 people turned out for a reception to thank our "Honor" research volunteers. Allan Levey, MD, PhD and James Lah, MD, PhD,



Allan Levey, MD, PhD

welcomed everyone and introduced ADRC researchers who provided an update on current research projects.



James Lah, MD, PhD

the effect of sleep apnea on memory at the October 24, 2008 reception to "Honor" research volunteers. Many in the audience had worn a finger pulse oximeter monitor (to monitor oxygen level in the blood) as a part of their Clinic visit. Results have been promis-



Don Bliwise, PhD

ing in suggesting that, in a few cases, cognition may have been improved if sleep apnea was identified and treatment was successfully implemented. "Changes in sleep patterns, including symptoms of sleep apnea like snoring and daytime sleepiness, are not uncommon in older people, and many persons are interested in knowing whether they have this sleep disorder," according to Dr. Bliwise.

Felicia Goldstein, PhD, provided an overview of her Diffusion Tensor Imaging study. While still gathering data, her study has



Felicia Goldstein, PhD

found that changes in the white matter of the brain can be detected very early in the preclinical stages of Alzheimer's disease in patients who have mild cognitive impairment.

Many ADRC research volunteers have participated in the "eye tracking" study. Although Stewart Zola, PhD could not provide results of the study—because it is still ongoing—he delighted the audience with magic tricks as he thanked them for participating. When the study is completed we will ask Dr. Zola to give us the results along with more magic tricks.

Current clinical trials seeking vol-



Stewart Zola, PhD

unteers were reviewed by Janet Cellar, RN, MSN and Deborah Stout, RN, BSN. Each clinical trial has different criteria for participants. Vaccine trials are underway and still seeking participants.

Many families of research volunteers who had died attended and together we "remembered" their loved ones. in a service led by chaplain Bridget Piggue, a member of the ADRC Education Core community advisory board. We are deeply grateful to these wonderful

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That's So Frustrating!

by Kenneth Hepburn, PhD



Many family members caring for loved ones with Alzheimer's say that the most difficult and troubling part of caregiving is dealing with the things the person does that are

inconvenient, disruptive, confusing, annoying, or dangerous. The savvy caregiver becomes a student of behavior, and a good first step in understanding behavior is to have a way to think about it. Linda Teri, a psychologist who has studied persons with Alzheimer's uses an A-B-C (Antecedent-Behavior-Consequence) model to teach caregivers ways to understand and deal with the behaviors of the persons for whom they provide care.

The key to using the model is remembering that all behavior has meaning.

In everyday life, if we wonder about the meaning of someone's action (behavior), we can simply ask why s/he did it (what was the antecedent).

We can also ask about how the person feels about the result of the action (its consequence). As usual, this is not so straightforward with Alzheimer's.

Caregivers have to try to figure out why something happened – what was the antecedent. Look carefully at the behavior as it is occurring; can you observe any clues in how the person looks or acts? Does the person seem to be confused, excited, angry, upset? What can you tell from looking at the person? Did an event trigger the behavior? Did something in the normal routine change?

If you think you understand the cause, the Antecedent, try changing it. Might the news show on the TV have confused the person? Was there too much or too little light in the room? Was the person asked to do too much or too little? Or there might be less obvious

causes. For instance, if the person is in pain or feeling unwell, s/he may not be able to tell you so, but it could produce unusual behavior.

If you have a hunch about the Antecedent, try doing something to change it. Turn to another channel or put music on rather than the TV. Make things easier to see in the room. Try changing what the person was doing, making it easier or harder. And check to see if there might be physical discomfort that you can do something about.

Also, try doing something about the Consequence. Instead of reacting to the behavior itself, try having a set of diversions that you can draw on. Taking the person out of the cycle of the difficult behavior (rather than reacting directly to it) may be an effective way to deal with it. However, if there is a persistent cause – some physical problem that the person cannot describe – the behavior may persist, and you may find it useful to consult your primary care provider.

Fay visits her mother Mae's home for their usual Wednesday lunch date. She arrives to find her mother acutely confused about the date and unable to focus enough to get dressed. Mae says to Fay, "I'm so glad you're here, daughter. There's a strange man in the basement and I think he wants to steal from me!" What is going on? Could Mae have developed dementia in the past week??

Delirium is a reversible cause of brain dysfunction resulting in the loss of cognition, memory and behavioral disturbance. Delirium may be misdiagnosed as an acute episode of schizophrenia, mania or as "typical of old age". If an older person presents to a health care setting (like the emergency department), a clinician may quickly assume that confusion is typical for the person and may misdiagnose it as dementia.

The best definition of delirium is that it is a syndrome. It is an acute confusional state characterized by de-

Delirium: A Reversible "Dementia"

by Monica W. Parker, MD

creased attention span, waxing and waning of symptoms. Symptoms may last for a few days or several months.

Delirium is often a symptom of serious illness, in some cases it may be the only symptom. It represents a **medical emergency** associated with increased morbidity (sickness) and mortality (death). Although it is often unrecognized and poorly managed, delirium is fairly common in older persons. Nearly 56% of all hospitalized patients develop delirium. Elderly patients undergoing orthopedic surgery will often have a post operative complication of delirium. Nearly 10% of all nursing home residents suffer from delirium.



There are many causes of delirium. They range from infection or low blood sugar to side effect of medications. Individuals with Alzheimer's disease are more susceptible to delirium. Seemingly small physical changes like dehydration or a low potassium can cause delirium in these persons.

Diagnosis of delirium is dependent on obtaining a thorough history of the present illness from caregivers and/or family. The biggest clue is the timing: delirium occurs quickly whereas dementia is a slow, insidious onset. Health care providers should obtain laboratory and radiologic studies to look for abnormalities. Resolution of delirium requires treating the cause. Medications that have been well tolerated may have to be changed. Delirium can be resolved. Delirium is not a progressive brain degenerative disorder like Alzheimer's Disease.

Clinical Trials & Research Studies · Spring 2009

Research Study	Eligibility	Contact Person
Vaccine Trials	<ul style="list-style-type: none"> • Diagnosis of mild to moderate Alzheimer's disease • Age 50 and older • Stable on medications for Alzheimer's for three months • Study partner available to accompany to all visits 	Deborah Stout 404-728-6590 dstout@emory.edu
Neuroimaging study	<ul style="list-style-type: none"> • Diagnosis of Alzheimer's disease or Normal cognition, Age 50 years and older • Right handed • 1 visit with MRI 	Andrea Kippels 404-728-6443 ajkippe@emory.edu
RAGE Inhibitor Study (Rage = Receptor for Advanced Glycation Endproducts)	<ul style="list-style-type: none"> • Diagnosis of mild to moderate Alzheimer's Disease • Stable on Alzheimer's medications for 4 months • Study partner available for all visits • 21 month study 	Ann Snider 404-728-6541 asnider@emory.edu
Emory ADRC Research Registry Longitudinal study of changes in memory and other cognitive skills	<ul style="list-style-type: none"> • Aging people over 65 with no memory problems • People of any age with mild cognitive impairment, Alzheimer's disease or other forms of dementia • Interested in participating in additional research studies at the Emory ADRC • Study partner available to participate in visits 	Katelyn Perkins 404-728-6950 kgperki@emory.edu
Lewy Body Disease	<ul style="list-style-type: none"> • Diagnosis of Lewy Body Dementia • Stable on medications • Willing to spend 72 hours in a sleep research lab • Willing to undergo lumbar puncture 	Donald Bliwise, Ph.D. 404-728-4751
Memory Rehabilitation Intervention in Amnesic Mild Cognitive Impairment	<ul style="list-style-type: none"> • Diagnosed with amnesic mild cognitive impairment • Study partner who can attend all cognitive rehabilitation sessions • Lives within 45-driving minutes of Wesley Woods Health Center at Emory University and/or will commit to come to all training sessions 	Noah Duncan 404-728-6544 nduncan@emory.edu
Cognitive Rehabilitation in Mild Cognitive Impairment	<ul style="list-style-type: none"> • Diagnosed with mild cognitive impairment • Willing to undergo functional MRI 	Ben Hampstead, PhD 404-712-5667 bhampst@emory.edu
Vision in Alzheimer's disease	<ul style="list-style-type: none"> • Diagnosed with early to middle Alzheimer's • Aging people with no memory problems • One three hour visit to the VA Medical Center • Virtual reality study 	Casey Bowden 478-951-1453 bowden.casey1@gmail.com
Registry for Remembrance: An initiative to increase awareness & participation in neurology research	<ul style="list-style-type: none"> • Ethnic persons with African Ancestry • Aging people over 60 with no memory problems or people of any age with mild memory problems or Alzheimer's • Study partner available to participate in visits 	Ezinna Anosike 404-728-6395 eanosik@emory.edu

Donations to the Emory Alzheimer's Disease Research Center · July-December 2008

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Two Generations of a Family Touched by Alzheimer's

By Susan Peterson-Hazan, MSW

Coe Hamling and his daughter Nancy Puckett came to the October 24, 2008 Emory ADRC event designed to "Honor" research volunteers. Their family has participated in many different types of research at Emory.

Nancy's husband, Larry Puckett, developed memory problems and was diagnosed with Alzheimer's disease at the age of 55. "We were devastated by the diagnosis" said Nancy. "We were eager to participate in research and Larry entered a clinical trial to test a new medication."

A few years earlier Nancy's mother, Betty had developed memory problems. Coe brought her to Emory for evaluation and she was found to have

mild cognitive impairment. Coe and Betty became much loved long term participants in the Emory ADRC Early Memory Loss Group. Always a charming woman and able to cover her memory loss, Betty was diagnosed with Alzheimer's disease several years later. Together they made the decision to enroll Betty in a clinical trial that was testing a new potential medication for Alzheimer's with Coe as her study partner. When the Emory ADRC began a genetic research program Betty and Coe decided to participate donating a blood sample and providing family medical history.

During the October 24th program a "Service of Remembrance" was led by Reverend Bridget Piggue for all re-

search volunteers who had died. Larry Puckett died in 2005 at age 62. Betty Hamling died in 2008 shortly after her 90th birthday. Their families honored the Emory ADRC by gifting their brains to our research program. Through their generous donations they continue to contribute to research.

However the death of loved ones did not end this family's commitment to research. Coe and Nancy are both now enrolled in our long term ADRC Honor Research Registry. They come in for annual evaluations of their own memory and thinking skills. They are committed to further research efforts to find a cure for the disease that has so touched their family.

Fronto-Temporal Dementia: Improving Quality of Life

Used with permission, Northwestern University Cognitive Neurology, ADRC

Language problems such as primary progressive aphasia (PPA) often coexist with fronto-temporal dementia (FTD). Here are some suggestions to help individuals with FTD and PPA and their families improve quality of life:

1. **Avoiding depression:** The family and physician should watch for non-verbal signs of depression, which include tearfulness, changes in sleeping or eating patterns, irritability, and withdrawal. A physician may choose to prescribe an antidepressant, which may help the patient become more engaged and hopefully feel better.

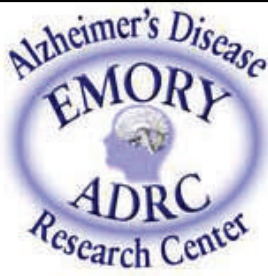
2. **Improving communication:** Introducing alternate modes of communication as early on in the disease as possible may help minimize frustration. Many families choose to work with a speech language pathologist to tailor alternative communication strategies. These may include a communication notebook (photographs of family and friends, emergency information and medications, pictures of hobbies and commonly visited places) that help bolster independence and allow the patient to communicate non-verbally with others. All language-impaired patients should carry a wallet card with a brief explanation of their condition and pertinent emergency information, so that they can communicate their situation quickly to anyone they interact with.

3. **Avoiding confrontation:** Confrontational situations may emerge when patients may not appreciate that they have experienced changes in personality or behavior. Poor judg-

ment is common, as are inappropriate behaviors such as telling offensive jokes, approaching strangers, sexual disinhibition, and indiscriminant spending. If a confrontation emerges, remember not to argue. Try to identify exactly what it is that is causing the situation, and understand triggers. Often, changes in volume or tone of voice or body language can indicate that the patient is upset. Pick your battles, and only intervene in really disruptive cases. Try to keep a sense of humor. Keep decision-making to a minimum to decrease confusion and frustration. Validate feelings and make them feel safe.

4. **Maximizing activity:** Adult day services and leisure programs provide socialization and structured daily activity. A hired companion who comes to the home may be able to provide some stimulation, help with language practice, or help get the patient out of the house for some exercise. Nonverbal activities such as listening to music, art activities, spending time with a pet, or completing nonverbal puzzles may be soothing and provide meaningful activity.

5. **Caregiver health:** Dementia caregiving can be very stressful, and it is important to stay healthy and fit. Make sure you take time for yourself, recruiting friends, family or professionals to provide respite. Identify activities that are relaxing and fun for you, and make time for them. **Support groups are available at the Emory ADRC beginning this summer. Stay tuned to our website for further details.**



Research Update: Spring 2009

Emory Alzheimer's Disease Research Center

Wesley Woods Health Center, 1841 Clifton Rd., Atlanta, GA 30329
 Grady Neurology Clinic, 80 Jesse Hill Jr. Drive SE, Atlanta, GA 30303
 404-728-6950 <http://med.emory.edu/ADRC/>

Dimebon Results Hold Hope

Dimebon, an antihistamine that was developed in Russia in the 1980's has recently been tested as a treatment for Alzheimer's disease. An article in the July 2008 journal *Lancet* found that Dimebon "was safe, well tolerated, and significantly improved the clinical course of patients with mild-to-moderate Alzheimer's disease." The group that received the medication showed improvement compared to the placebo group. The target of Dimebon is believed to be the energy factories within cells, mitochondria. According to James Lah, MD, PhD., Associate Professor in the Department of Neurology at Emory University, "*This study was remarkable for the consistent beneficial effects found by multiple measures. Importantly, the difference between individuals receiving the drug compared to those receiving placebo increased over time, suggesting that Dimebon may slow disease progression.*" A larger clinical trial testing Dimebon in patients with mild to moderate Alzheimer's will begin spring 2009.

Gene therapy: A 21st Century Approach

A 2005 report in the journal *Nature Medicine* found that a gene therapy, Nerve Growth Factor (NGF) could be transferred to people safely. Eight people with Alzheimer's disease were enrolled in this study and showed improvement on the study measures. However, no placebo group was enrolled in this study to provide comparison. Rush University in Chicago tested a less invasive method to administer NGF to a small number of people with Alzheimer's disease and found similar results.

These small studies were intended to help define dosing and evaluate safety. Gene therapy using NGF is entering into Phase II trials that will enroll a larger group of people to determine potential risks and evaluate effectiveness. This unique trial involves surgical delivery of NGF to prevent the degeneration

and death of cells in a specific region of the brain. Although surgery always involves risk, earlier studies provided good safety data. If effective, the gene therapy may provide long-lasting benefits after a single treatment. A clinical trial sponsored by the National Institutes of Health in collaboration with Ceregene®, will begin in spring of 2009.

Vaccine Trials Enrolling

Several vaccine trials are underway and still enrolling volunteers. These still-experimental vaccines or immunotherapies target betaamyloid, a naturally occurring protein that clumps together and forms plaques in the brains of Alzheimer's patients. The clumps appear to damage brain cells. "*This is an exciting time for those who treat and care for people with Alzheimer's,*" says Allan Levey, MD, chairman of the Department of Neurology at the Emory University School of Medicine. "*By harnessing the patient's own immune system, it may be possible to change the course of the disease, rather than simply treat its symptoms.*"

New publication on Alzheimer's Research

The "2007 Progress Report on Alzheimer's Research: Discovery and Hope" was published late 2008 and is available through the National Institute on Aging. The report is available online or a copy can be ordered at <http://www.nia.nih.gov/Alzheimers/>.

Learn More

Visit the Emory ADRC website at <http://med.emory.edu/ADRC/>, call 404-728-6950 or email speter2@emory.edu for information on clinical trials in Georgia. Further details about the studies in this Research Update are available at:

<http://www.nia.nih.gov/Alzheimers/ResearchInformation/ClinicalTrials/>.

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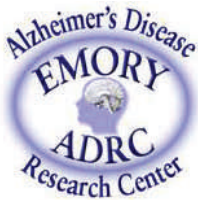
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404-616-4567

To Register for a Class:

Please call Susan Peterson-Hazan at 404-728-6273 at least one week prior to the beginning of each class.

Event	Date	Location
Early Memory Loss Group <i>(Co-sponsored by the Alzheimer's Association, Georgia Chapter)</i>	A 8-week class that meets: Friday 10:30 – 12:00 September 11 th – October 30 th , 2009	All Classes will be held at the: Wesley Woods Health Center 3 rd floor conference room 1841 Clifton Rd. Atlanta, GA 30329
Caregiver Challenges: Everything You Want to Know About the Middle Stage of Alzheimer's Disease <i>(Sponsored in part by a grant from the Wesley Woods Foundation)</i>	A 6-week class that meets: Friday: 10:30-12:00 November 6 th – December 18 th , 2009	
Late Stage Alzheimer's Disease <i>(Sponsored in part by a grant from the Wesley Woods Foundation)</i>	A 4-week class that meets: Friday: 10:30 – 12:00 May 15 th – June 5 th , 2009	



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