

Emory University School of Medicine Alzheimer's Disease Research Center

THE REGISTRY FOR REMEMBRANCE

Monica Willis-Parker, MD



"The Registry for Remembrance advances the scientific goals of Alzheimer's Research and enables equitable participation of the minority community. It is further

intended to close the gap in understanding between research and resource use in the minority community through education and participation."

The preceding mission statement represents the intent behind the establishment of the REGISTRY FOR REMEMBRANCE (REGISTRY), a community-academic partnership between the Emory Alzheimer's Disease Research Center (ADRC) and the Atlanta community, to encourage and increase the participation of underrepresented persons, particularly African Americans, in neurologic research. The Registry is composed of persons aged 65 and over who are committed to participation in ongoing neurologic studies at the ADRC.

The low participation rate of Americans of African ancestry in clinical research directly impedes biomedical research and the development of clinical studies relevant to this segment of the US population. This results in a health disparity with regard to early diagnosis, prevention and treatment of neurologic disease. The African American community's mistrust of research institutions and a limited understanding of the research process act as barriers that must be overcome to improve this current disparity. With the accelerating pace of basic and clinical research, the urgency of the problem grows. Chronic underrepresentation in research limits our understanding of numerous important questions that will impact the health and medical treatment of aging African Americans.

In order to take action on this issue, a team of persons including myself, a primary care physician, Dr Ken Hepburn, an experienced researcher, as well as cognitive neurologists, Drs. Allan Levey

and James Lah, came together to discuss the lack of African Americans in current clinical research studies about one year ago. This discussion was broadened to include leading community "elders" in religion, business, civic/social and professional societies of the Atlanta community. These conversations have resulted in the formation of a community advisory board that assists with access to the community and in the dissemination of information regarding the Registry and current neurologic studies and research practice. These discussions continue with regularity as our Registry matures. As the Registry for Remembrance matures, we hope to develop a city/region wide initiative that will serve as a resource for other areas of Health research and include the participation of other Atlanta based academic institutions (Morehouse, Georgia Tech), Corporations (Coca-Cola) and foundations.

On April 19, 2008, we will hold our first public community forum at St. Philip AME Church in East Atlanta.

LIONS, TIGERS, AND BEARS AT GRADY *Angela Ashley, MD*

and Fulton boards to approve Grady's not for profit status, we are now positively positioned to continue our mission of providing care and assistance to the some of our city's most remarkable citizens. Thanks to all of you who supported us with your letters and prayers! And as a special bonus to those of you who are interested enough to have read this entire section, we are disclosing the secret to rapid scheduling at the clinic. While our next available appointment for new patients remains almost a year away, patients may be seen in as little as one to two weeks by placing their name on the wait list for cancellations. Whether you are concerned about symptoms of memory loss in a friend or family member, or have a question about your own mild forgetfulness, we will be happy to provide assistance with diagnosis, treatment plans, healthy lifestyle instruction and planning for the future. Please call our social worker, Ms. Sheryl Sledge, at 404-616-5975 with any questions or requests for appointments.

Lions, tigers and bears? It was really budgets, politics and the media, but it felt just as stressful to the faculty, staff, patients and supporters of the Grady Health System. But after two years of uncertainty, it appears as if the future of the Grady and the Memory Clinic is not only bright but stable. With the recent votes by the Dekalb



Control – A Savvy Caregiving Outlook *Ken Hepburn, PhD*



Freedom. Rights. Autonomy. Being in charge of one's own fate. These are deep values in our traditions. Civil behavior is anchored in principles of respect for a person's right to make his or her own choices. Marriages and other family relationships are grounded in the expectation that all parties can and will act independently and responsibly.

Most family members bring this profound valuing of autonomy to their role as caregivers. However, the demands of the role can set up powerful and disturbing conflicts in the caregiver related to the issue of autonomy – and control. Caregivers have to make choices for

and about the person for whom they provide care. Such choices are not easy in themselves. If the difficulty of making them is mixed with the feeling that they also involve violating the rights of the person or violating the existing relationship, then they can also be the source of great distress for the caregiver.

For the Savvy Caregiver, the reconciliation of this apparent dilemma is the recognition that the disease that is at work is gradually and progressively limiting and eroding the person's capacity for free and informed choice. The Savvy Caregiver recognizes that some choices are possible. There are some things that the person can do and choose that are well within his or her capacities. But others are not.

Consider a range of choices and decisions: what shirt to wear; what to order at the restaurant; whether to take medications according to schedule; whether to use the stove; whether to drive to the

store; whether to sell the house; whether to move to a nursing home; whether to refuse resuscitative treatment. The person may be able to sort through all, some, or none of these decisions in a manner that is comfortable and not confusing and to arrive at decisions that are sensible and not arbitrary.

The Savvy Caregiver is constantly figuring out where the person is along that spectrum of capability. S/he encourages choice where there is capacity. But she removes the person from the situation of confusion, frustration, and upset that is possible when decision-making is out of range for existing capacity. Taking control like this – based on a respect for the person's remaining powers – is part of caregiving. It is kind (fending off confusion) and respectful (engaging the person who is still present). It is also a savvy thing to do: it wards off potentially distressing situations and makes the day go more smoothly – a true sign of good caregiving.

The MCI Partners Program

A 5-Week Group Program for Persons with Mild Cognitive Impairment and their Family Care Partners *Marsha L. Lewis, PhD, RN*



Planning for living with a chronic condition is essential. Each of us should consider what our lives may be like as we get older. What plans can we make now to ease the burden for ourselves and our families as

time goes by? This program is offered at no charge to participants and their program partners. It aims to help those who attend to understand the condition and help them develop ways to manage it.

This two-hour per week class is being tested to see if those who take part find the program helpful and acceptable. Each session will be led by two professionals

with backgrounds in elder care, nursing, or social work from Emory Healthcare and the Nell Hodgson Woodruff School of Nursing at Emory University. Sessions will include short talks about the diagnosis of MCI, opportunities for discussion with the leaders and other members of the group (up to ten people) about living with MCI, activities that help you develop ways to address symptoms, and strategies to promote and maintain a healthy brain. Participants will have opportunities to try the activities and strategies at home, be coached by professionals, and practice developing plans for the future and making decisions.

This group will meet on a day and time agreed upon by all group members. Each program will enroll up to five MCI and

care partner dyads. All participants will meet together in the sessions, although the group will break into two groups at times for discussions.

Persons diagnosed with MCI and meet the following requirements are eligible to participate: meet diagnostic criteria at a pre-program screening, have a "program partner" (spouse, family member, close friend) who has contact at least two times per week and is willing to come to the five sessions, and commit to coming to all five sessions. An individual with serious visual or hearing impairment, history of reading or written expression disability may not qualify for this program. If you are interested in participating or receiving more information, please contact **Noah Duncan at 404-728-6544**.

Emory ADRC Spring 2008 Research Update:

Healthy Living Prevents Alzheimer's Disease...Or Does It?

April 19, 2008 ▪ 11:00am

St. Philip AME Church - Fellowship Hall, 240 Candler Road, Atlanta, GA 30317

Donations to the Emory Alzheimer's Disease Research Center ▪ July 2007 through December 2007

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In Memory of Ms. June Atwood Bullard Ms. Olivia Ann Bullard Dr. Evan M. Torch			

Contributions: If you would like to make a contribution to support the Alzheimer's Disease Research Center, please use the following contribution form.

Enclosed is my tax deductible gift of \$ _____ . Please note that this contribution is:

In Memory of: In Honor of: _____

Please send acknowledgement of this donation to:

Name: _____

Address: _____

City: _____

State: _____

Zip: _____

Address: _____

City: _____

State: _____

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Please make checks payable to:

Emory Alzheimer's Disease Research Center
c/o Emory Univ. Health Sciences Development
1440 Clifton Road, Suite 112
Atlanta, Georgia 30322

ADRC Pilot Projects
Stacy Heilman, PhD

As part of our National Institute on Aging grant award, the Emory ADRC conducts a pilot grant program for Emory researchers to collect new data related to understanding the causes of, earlier detection of and possible treatments for Alzheimer's disease (AD). Over the past four years, we have awarded thirteen one-year pilot projects with topics ranging from testing interventions to lessen the symptoms of AD, to basic science studies geared toward understanding what happens in the brain of AD patients, to testing novel ways that may allow us to detect AD earlier in the disease progression. All of these studies rely on the resources of the Emory ADRC including blood and brain tissue donated by our ADRC registry participants as well as our registry volunteers who participate in studies.

Soon we will begin the fourth year of this program. The newly awarded studies include non-invasive brain imaging for early detection of AD and strategies to improve memory function in patients at risk of developing AD. If you are over the age of 65 and think you may be interested in participating in these or other ADRC affiliated studies, you can contact us at 404-728-6950 to express your interest and learn more about the time commitment involved in being a part of our ADRC registry.

Without our ADRC registry volunteers we would not be able to study these important questions. Our brain donation program is critical in allowing scientists to uncover the causes of AD and will likely play a vital role in developing treatments and a cure for this devastating disease.

Clinical Trials & Research Studies Spring 2008

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 	Janet Cellar 404-728-6453 jcellar@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 	Heather Tovey 404-728-6589 htovey@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 or • People with Mild cognitive impairment or • Alzheimer's disease or • Other forms of dementia 	Megan Vucovich 404-728-6590 mmvucov@emory.edu
Lewy Body Disease	<ul style="list-style-type: none"> • Diagnosis of probable or possible 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 Amnestic Mild Cognitive Impairment	<ul style="list-style-type: none"> • Diagnosed with amnestic 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
The Mild Cognitive Impairment Partners Program	<ul style="list-style-type: none"> • A 5-Week Group Program for Persons with Mild Cognitive Impairment and their Care Partner • Diagnosed with mild cognitive impairment • Study partner who can attend all groups 	Noah Duncan 404-728-6544 nduncan@emory.edu
Frontotemporal Dementia Caregiver Study	<ul style="list-style-type: none"> • A family member with frontotemporal dementia 	Susan Peterson-Hazan 404-728-6273 speter2@emory.edu

Alzheimer's Disease Vaccines....A New Frontier in Alzheimer's Disease Research?



On December 6, 2007 the ADRC sponsored a panel discussion on the current status of vaccine trials and other immunotherapies for the treatment of Alzheimer's disease. Over 100 people attended the session at the Nell Hodgson Woodruff School of Nursing on the Emory campus. The event was sponsored by the School of Nursing, the Georgia Chapter of the Alzheimer's Association and the Emory Yerkes National Primate Center.

The panel was moderated by Ken Hepburn, PhD the director of the ADRC Education Core. Panel members included Allan I.

Levey MD, PhD, Professor and Chair of the Emory Department of Neurology and Principal Investigator of the ADRC; James J. Lah, MD, PhD Director of the Emory Cognitive Neurology Program; Lary Walker, PhD, Research Professor, Yerkes National Primate Research Center; and Janet Cellar RN, CNS. Dr. Walker provided the audience with an overview of the science of vaccines. Dr. Levey and Lah addressed some of the recent evidence for the potential benefit of vaccines for the treatment of AD while Janet Cellar provided information about upcoming vaccine trials at Emory.

The audience demonstrated their excellent understanding of the current status of clinical trials and in particular of the upcoming vaccine trials by asking many very insightful questions of the panel. The histories of vaccine research and in particular of the

early vaccine trials for AD were reviewed including the early experience of side effects in the first vaccine trials. The current vaccine strategies were discussed; in particular, as they relate to the current trials as well as the measures that are in place to help protect the health and safety of study participants. Three vaccine trials will be conducted at Emory in the upcoming months. If you are interested in learning more about both the upcoming vaccine trials as well as other possible clinical trial participation please contact the Emory ADRC at 404-728-6950.

Please join us at St Philip AME Church for the next Research Update on April 19, 2008 at 11am as our experts discuss the relationship between lifestyle and Alzheimer's risk in "Healthy Living Prevents Alzheimer's Disease... Or Does It?"

How Are Genes Involved in Alzheimer's Disease

Ami R. Rosen, MS, CGC, Genetics Counselor

Many genes are involved in either predisposing or causing people to have Alzheimer's disease (AD). So far one gene has been identified that, in a certain form, predisposes people to late onset AD and three genes have been found to cause early onset AD when there is a mutation in one of these genes. The Emory ADRC is actively involved in the search for the other genes that predispose people to and cause AD through our work with the ADRC Registry and other genetic and protein research studies.

To understand how genetics is involved with any disease, it's important to realize that every person has two copies of every gene, even the genes implicated in disease. We inherited one of the copies from our mother & one from our father. When a mistake or mutation in a gene exists, that is when a gene can cause a disease. In the case of AD, if there is a mutation in one copy of a person's APP, PSEN1 or PSEN2 gene, they will develop early onset AD. These mutations are inherited in an autosomal dominant fashion which means that any child of a person with this mutation has a 50% chance of inheriting the mutation. This 50% chance comes from the fact that the parent with the mutation in one copy of a gene has a total of two copies of this gene and will only give one copy to any child.

The ApoE gene can predispose people to develop late onset AD if they have a certain form of the gene and can protect people from AD if they have another. The ApoE gene has three forms: 2, 3, & 4. Think of these forms of the gene using the following simile: the ApoE gene is like a shirt, you can buy a shirt with long sleeves or short sleeves or no sleeves at all; the shirt is still a shirt and will work



well as a shirt regardless of its form. However, a long sleeve shirt is best for cold weather while one with no sleeves won't work well in the winter at all, and short sleeves fall somewhere in between. In this same manner, the 2 form of the gene protects people from AD, the 4 form of the gene predisposes people to AD, and the 3 form of the gene (which most people have two copies of) neither protects nor predisposes. Since we all have two copies of the ApoE gene, different people can have different combinations of these forms, even peo-

ple in the same family. A person with two 2's, written 2/2, will be doubly protected from AD. (This is very rare.) A person with two 4's will be doubly predisposed and will tend to develop AD a little earlier than people with only one 4 or with none at all. Most people have at least one 3 and their other copy of the gene is either a 2, 3, or 4. Those with a 2/3 will be protected, those with a 3/3 will have about population risk, and those with 3/4 will have an increased risk to develop AD .

Clinical testing is only available for the PSEN1 gene mutations and for ApoE. Occasionally doctors will use these tests to help them determine someone's diagnosis. However, mutations in PSEN1, PSEN2, and APP only account for about 2-3% of all cases of AD, so these tests are of limited clinical use. ApoE 4 status is associated with 40-60% of AD cases, but since it does not often help to know this status for treatment, it is not often ordered. This testing is not recommended for people with no symptoms of AD.

We still have a lot of work to do trying to discover what other genes and environmental factors are implicated in the development of AD. However, research is ongoing and with your help, both as volunteers and supporters, we will figure out the rest of this puzzle.

CONTACT US

Emory Alzheimer's Disease Research Center

Wesley Wood Health Center
1841 Clifton Road, NE
Atlanta, GA 30329
404-728-6950

<http://med.emory.edu/ADRC>

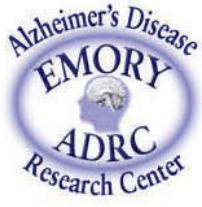
Memory Assessment Clinics

Wesley Woods Health Center 1841 Clifton Road, NE Atlanta, GA 30329 404-728-4936	Grady Memorial Hospital 80 Butler Street, SE Atlanta, GA 30335 404-616-4567
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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
Caregiver Challenges: Everything You Want to Know About the Middle Stage of Alzheimer's disease (Sponsored in part by a grant from the Wesley Woods Foundation)	A 6-week class that meets: Fridays: 10:30 – 12:00 April 4, 11, 18, 25 & May 2, 9	
Late Stage Alzheimer's Disease (Sponsored in part by a grant from the Wesley Woods Foundation)	A 4-week class that meets: Friday: 10:30 – 12:00 May 16, 23, 30 & June 6	All classes will be held at the: Wesley Woods Health Center 1841 Clifton Road Atlanta, GA 30329
Early Memory Loss Group (Co-sponsored by the Alzheimer's Association, Georgia Chapter)	An 8-week class that meets: Friday: 10:30 – 12:00 September 5, 12, 19, 26 & October 3, 10, 17, 24	
Caregiver Challenges: Everything You Want to Know About the Middle Stage of Alzheimer's disease (Sponsored in part by a grant from the Wesley Woods Foundation)	A 6-week class that meets: Friday: 10:30 – 12:00 October 31, November 7, 14, 21 and December 6, 12	



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Atlanta, GA 30329

