



PATHWAYS

Moving Toward a Cure

Fall 2007

Message from the Director



Steven T. DeKosky, MD
Director

Dear Friends,

This issue of *Pathways* shows the broad range of research and clinical care in Alzheimer's disease (AD) and related disorders, both nationally and here at the University of Pittsburgh Alzheimer Disease Research Center (ADRC).

Among the many topics discussed in this issue

are advances in understanding the role and importance of caregivers in the care of people with AD, the interactions of genetics and behavioral disturbances (such as hallucinations or delusions), and national and local research programs in which you can participate. We are hopeful that this information will increase your understanding of the disease and allow you and your loved one to contribute to our fight against it by working with our researchers.

Among a large number of drugs in development, two oral medications—Alzhemed and Flurizan—have stimulated a great deal of discussion because they are the most advanced (in testing) of the medications directed against amyloid pathology—a key factor in the development and progression of the disease. The ADRC participated in the clinical trials for these medications, offering the ability to participate in these studies to our patients and families, and we will present the findings of these and other trials to you as they are released. In September 2007, the company sponsoring the study, Neurochem, announced that the results of the North American study of Alzhemed did not have statistically significant positive results. While the data continue to be analyzed, we await the results of a second trial as well as additional analysis of the North American trial.

Caregivers: The Forgotten Patients

If you care for a family member with dementia, you probably already recognize the importance of your role as “health care manager.” Since you are directly involved in day-to-day care, you provide information about your relative's medical history, symptoms and treatments. When new medicines are given, you keep an eye out for side effects or problems and make sure your relative takes them correctly. You probably also encourage your family member to eat a healthy diet and follow other doctor's orders. Caregivers are the “eyes and ears” of the medical team for the person with dementia.

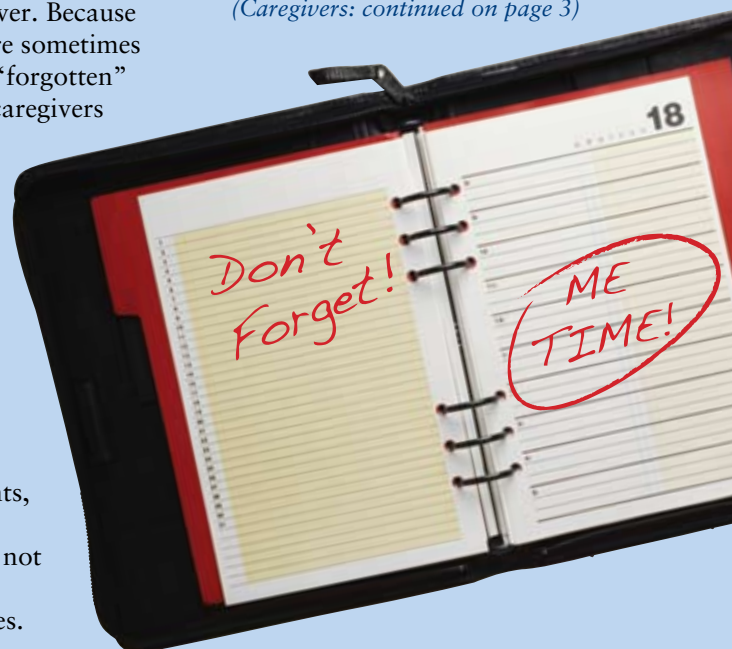
Unfortunately, caregivers don't always remember to talk to their own physicians about themselves! In fact, many times the caregiver's own doctor doesn't realize that the person he or she is treating is a dementia caregiver. Because of this, caregivers are sometimes called “hidden” or “forgotten” patients. Although caregivers are at greater risk for a variety of health problems including sleep disturbances, high blood pressure, diabetes, and depression, they are also more likely than non-caregivers to skip their own medical appointments, to neglect taking medications, and to not take enough time to recover from illnesses.

Studies have shown that the main reasons caregivers neglect their own health are that they feel they should be able to manage on their own, or that they don't think they have time for medical visits for themselves. Sadly, in the worst-case scenario, caregivers may become so ill that they become unable to continue to take care of their loved ones.

Don't let that happen to you! If you are caring for someone with dementia, be sure to let your own doctor know. Here are some suggestions to help you stay as healthy as possible:

- Write down what you want to tell the doctor about your situation before your appointment, so you can make good use of your time. Be sure to mention any difficulties that may be impacting your

(Caregivers: continued on page 3)



Volunteers Needed for Clinical Trials

Pittsburgh Compound B (PIB)

Description

This study will use PET imaging to determine how amyloid changes across stages of severity in AD and whether amyloid is present in elderly individuals without memory problems.

Study Length

Varies

Study Requirements

- 30 years of age or older
- Healthy individual or diagnosis of probable AD or diagnosis of mild cognitive impairment (MCI)

Compensation

Up to \$200 per year

REFLECT-3 Study

Description

Previous research has shown that rosiglitazone (a diabetes drug), in a new extended-release formulation, may benefit AD patients and that this benefit may be related to a patient's genetic makeup. This study will test the efficacy and safety of the new extended-release formulation of rosiglitazone when added to standard approved drug treatment with acetylcholinesterase inhibitors.

Study Length

Approximately one year

Study Requirements

- 50–90 years of age
- Diagnosis of probable AD
- Not currently taking Namenda
- Have a reliable study partner

Tolcapone COMT Inhibition and Cognitive Enhancement in AD

Description

In this six-week study, we will test whether a drug called Tolcapone can improve the attention and memory of patients with mild to moderate AD. Participants will undergo repeated cognitive and behavioral testing and have blood analysis to determine tolerability.

Study Length

Six weeks

Study Requirements

- 50–90 years of age
- Diagnosis of probable AD
- Have a reliable study partner

Optional Phase

Patients may continue to take Tolcapone following study termination.

For information about the Reflect-3 study, contact MaryAnn Oakley at 412-692-2721 or oakleym@upmc.edu; for the Tolcapone COMT study, contact Patricia A. Wilkosz, MD, PhD, at 412-692-2700 or pawst19@pitt.edu; and for the PIB study, contact Claire McConaha at 412-692-2727 or cwm15@pitt.edu.

Caregiver Studies

Making Sense of MCI: Patient and Family Perspectives

Description

To learn how those diagnosed with mild cognitive impairment (MCI) and their family members make sense of—or come to terms with—their symptoms and diagnosis

Study Length

A one-time interview lasting approximately 45 minutes

Study Requirements

Individuals diagnosed with MCI who have a family member willing to answer questions about them

Self-Management and Resource Training (SMART) Study

Description

To determine if a self-management educational program strengthens the personal resources (physical and/or mental) of men and women living with a spouse who has mild memory problems

Study Length

Three months

Study Requirements

Spouse or live-in partner of an individual diagnosed with mild cognitive impairment (MCI)

(Caregivers: continued from page 1)

- health. For example, let the doctor know if your family member is waking you up at night or if assisting with bathing and dressing is making your arthritis pain worse.
- At every medical visit, tell your doctor if you have noticed any changes in your energy level, sleep, appetite, weight, or mood. These can be signs of depression or other health problems that can be treated.
 - If your caregiving situation makes it difficult to follow your doctor's recommendations, let him or her know. For example, if you are unable keep medical appointments because your family member cannot be left alone, or are having difficulty following a special diet because your relative's eating habits have changed, your physician may be able to suggest alternatives.
 - Ask your doctor or nurse about services in the community and in your particular health care system for helping caregivers of persons with dementia and older adults. Even if you feel that you don't need such services right now, getting on a mailing list or having a list of resource contacts near the phone may prove very useful down the road.
 - Make a plan for handling medical emergencies that does not rely on the person with dementia to provide assistance in a crisis. If you fell at home and broke a hip, how would you get help? A person with even mild dementia may not be able to respond appropriately in an emergency.

- Make plans for overnight or longer term help with caregiving in the event of illness. If you needed to be hospitalized overnight, who could stay with your family member? If you needed longer term hospitalization, where would your care recipient go?

Research has shown that when caregivers work closely with their doctors to manage their own levels of stress and health, their hospitalizations and emergency room visits are reduced, and persons with dementia are able to remain at home for a longer period of time. Taking care of yourself is not selfish—it's essential to providing good care for your loved one and helps ensure that both of you can have a good quality of life for a longer period of time.

This article is an exact reprint from the University of Washington, Seattle, Wash. ADC Name: UW ADRC, Location: Seattle, Wash., Contact: logsdon@u.washington.edu, Publication Date: Spring 2006

Alzheimer's Disease: A Mini-Residency for Health Professionals

Program Goals

Offered by the University of Pittsburgh Alzheimer Disease Research Center, Alzheimer's Disease: A Mini-Residency for Health Professionals provides an opportunity to learn the principles of working with families facing cognitive impairment and to experience and understand current research in the field of Alzheimer's disease (AD) under the guidance of a preceptor.

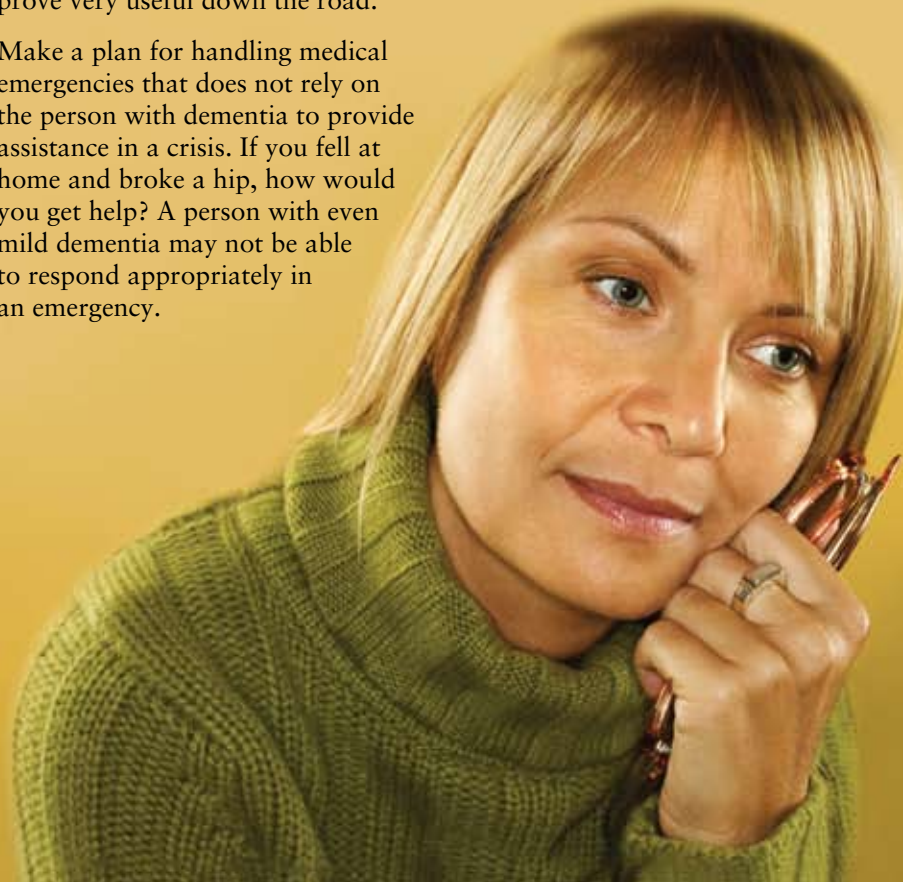
This program enhances the quality of life for people facing AD or another form of dementia by increasing awareness and understanding of clinical, research, and advisory skills. A major goal is increased understanding and use of a multidisciplinary approach to patient care.

Opportunities

Alzheimer's Disease: A Mini-Residency for Health Professionals offers many opportunities. Sessions include: Diagnosis and Clinical Evaluation, Physical Changes in Normal Aging, Neuropsychology of Memory, Accessing Community Resources, Etiology of Alzheimer's Disease, and Management of Behavioral Problems.

Application

The program is available in a two- or three-day format for interested physicians, psychologists, social scientists, neuroscientists, medical students, graduate students, post-doctoral fellows, nurses, social workers, physician assistants, health care administrators, physical therapists, occupational therapists, and members of the clergy. To allow for individualized scheduling, a short statement of interests, goals, and background is required with the enrollment application. Participants must be supported by their own institution. A fee will be charged for materials. For more information, contact Education and Information Coordinator MaryAnn Oakley at 412-692-2721.



International Prevention Conference Highlights

More than 1,000 dementia experts from around the world came together at the Alzheimer's Association International Conference on the Prevention of Dementia in June in Washington, D.C., to address how we can prevent Alzheimer's disease (AD) from becoming a global health crisis.

The conference is a multidisciplinary forum that brings together professionals from the fields of research, drug discovery, medicine, care, and public policy. Some of the findings presented at the conference include the following:

- The latest worldwide estimate of AD prevalence shows that 26.6 million people were living with the disease

in 2006. The researchers predict that global prevalence of AD will nearly quadruple by 2050 to more than 100 million people.

- New studies suggest that early detection of AD may be possible by identifying a gene "signature" in blood or combined MRI/PET analysis.
- Treating heart disease risk factors may slow AD progression. Evidence continues to accumulate suggesting that cardiovascular disease and AD share many risk factors and that addressing them (i.e. aggressively treating hypertension, lowering cholesterol levels, exercising

regularly) reduces an individual's risk of developing AD as well as heart disease.

- Updates were provided on studies of two new medications that have completed (Alzhemed) or are about to complete (Flurizan) their initial Phase III trials. Pitt's ADRC participated in both of these trials. While final results of the Alzhemed trials were expected at this conference, statistical issues delayed any announcement of the findings. In September 2007, the company announced that the study did not show a statistically significant benefit. Please see Message from the Director, page 1, for more information.

The Alzheimer's Association International Conference on the Prevention of Dementia is held every other year in Washington, D.C., and the International Conference on Alzheimer's Disease and Related Disorders convenes in the intervening years to allow large-scale research forums to occur annually and keep research moving forward.

A number of Pitt ADRC investigators (names listed in bold type) contributed publications at the meeting:

"The Ginkgo in Evaluation of Memory (GEM) Study Design, Recruitment, and Incident Dementia Rates: A Preliminary Report" by **Steven T. DeKosky**, Annette Fitzpatrick, Diane Ives, **Judith A. Saxton**, Jeff Williamson, **Oscar L. Lopez**, Gregory Burke, Linda Fried, Lewis H. Kuller, John Robbins, Russell Tracey, Nancy Woolard, **Leslie O. Dunn**, Richard Kronmal, Richard Nahin, and Curt Furberg

"Predicting an Individual's Risk of Developing Dementia. The Cardiovascular Health Cognition Study" by Deborah E. Barnes, Kenneth E. Covinsky, Lewis H. Kuller, **Oscar L. Lopez**, and Kristine Yaffe

"Cortical Amyloid Deposition Related to Failure of Hippocampal Activation" by Reisa Sperling, Pete LaViolette,

Eli White, J. Alex Becker, Erin Moran, Matt Gregas, **William Klunk**, **Chet Mathis**, **Julie Price**, Alan Fischman, Dennis Selkoe, Dorene Rentz, and Keith Johnson

"Quantitative Evaluation of PIB, PET, and FDG PET in Early Cognitive Impairment" by Val J. Lowe, Brad Kemp, Clifford R. Jack, **Chester A. Mathis**, **William E. Klunk**, and Ronald Petersen

"Early Detection of Alzheimer's Disease-Linked a β Peptide Accumulation in the Lens by Non-invasive Quasi-elastic Light Scattering" by Juliet Moncaster, Robert D. Moir, Sling Fu, Anca Mocofanescu, Suqian Lu, Weilan Xu, Oliver Chadwick, Jack T. Rogers, Martin Sadowski, Thomas Wisniewski, **William E. Klunk**,

Chester A. Mathis, John I. Clark, Rudolph E. Tanzi, and Lee E. Goldstein

"Correlation of Regional in VIVO Pittsburgh Compound-B (PIB) Retention with In Vitro PIB, A β Levels, and Amyloid Plaque Density: Validation of PIB-PET in Postmortem Human Brain" by **Steven T. DeKosky**, **Chet Mathis**, **Julie C. Price**, **Milos D. Ikonovic**, **Ronald L. Hamilton**, Eric E. Abrahamson, Willam R. Paljug, Manik L. Debnath, Caroline E. Hope, Barbara A. Isanski, **Nikolaos D. Tsopelas**, Brian J. Lopresti, Scott Ziolko, Wehzu Bi, and **William E. Klunk**



Congratulations to Thomas Baumgartner Jr. and Beth Sarles for earning their Master of Public Health degrees from Pitt in June 2007. Hats off to you both!



Pictured from left to right at the first annual Star Luncheon are honoree Rose Marie Zilich, ADRC Administrator Leslie Dunn, and Mrs. Zilich's daughter Denise Parks.

Luncheon Commemorates Family Star

The first annual STAR Luncheon to benefit the ADRC took place April 21, 2007, in memory of former ADRC patient Joseph N. Zilich.

The Zilich family created the luncheon in honor of their mother, Rose M. Zilich, an extremely strong woman in mind, body, and soul. Mrs. Zilich single-handedly cared for her husband during many, many months of his disease and deterioration. Often putting her own health aside, she listened and learned what she needed to do to be able to care for him at home and to be able to keep him at home as long as possible.

One year while Mr. Zilich was still in good health, he took some scrap wood and a set of white lights and made his wife a beautiful star for the large picture window that adorns the front of their home. Even in failing health and mind, Mr. Zilich still remembered and loved that special star he created for his dear wife.

It is the hope of the Zilich family that through the creation of the STAR Luncheon, and the generous donations made to the ADRC at the event, that a cure for Alzheimer's disease will be found in our lifetime.

Staff Spotlight

Psychiatric Social Worker

Thomas C. Baumgartner Jr., MPH, MSW, LSW

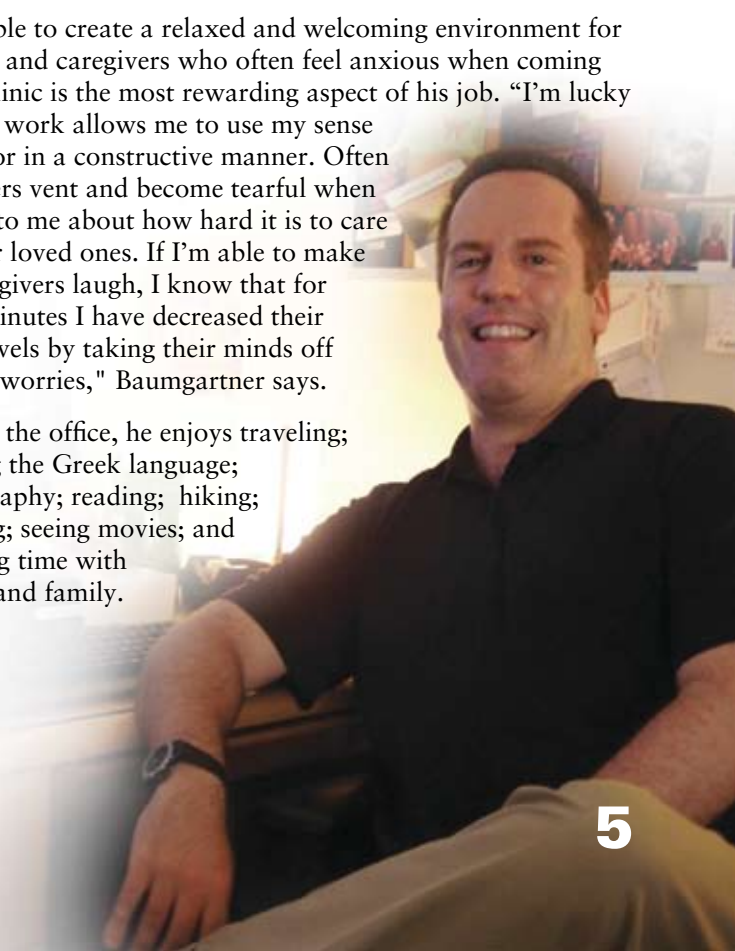
Thomas Baumgartner firmly believes that in his line of work, laughter is one of the best medicines around.

In his current position, Baumgartner carries out initial and annual psychosocial assessments of patients; provides emotional support to caregivers and educates them about community resources; works with caregivers to develop strategies that help keep patients safe, active, and vital at home and in the community; screens prospective patient applications; serves as a judge on the Alzheimer's Association's annual Caring Touch Award committee; coordinates clinical drug trials; facilitates informal roundtable discussions at various Alzheimer's disease events; and administers neuropsychological testing.

Baumgartner has been employed by the ADRC for 12 years. He started as a work-study student in 1995. After obtaining his bachelor's degree in social work from Pitt in 1997, he progressed to administering neuropsychological testing. He was hired in his current position as a psychiatric social worker in 1999 after obtaining his Master of Social Work degree from Pitt and becoming a licensed social worker. Additionally, Baumgartner earned his Master's of Public Health degree from Pitt in June 2007.

Being able to create a relaxed and welcoming environment for patients and caregivers who often feel anxious when coming to the clinic is the most rewarding aspect of his job. "I'm lucky that my work allows me to use my sense of humor in a constructive manner. Often caregivers vent and become tearful when talking to me about how hard it is to care for their loved ones. If I'm able to make the caregivers laugh, I know that for a few minutes I have decreased their stress levels by taking their minds off of their worries," Baumgartner says.

Outside the office, he enjoys traveling; learning the Greek language; photography; reading; hiking; camping; seeing movies; and spending time with friends and family.



In Memoriam



The University of Pittsburgh Alzheimer Disease Research Center thanks the following individuals and companies for their generous donations received February 1, 2007–June 30, 2007.

In Memory of Emma & Peter Anderson
Elaine A. Dively

In Memory of Esther Ascheim
David A. Lovejoy

In Memory of Mabel M. Baker
Gretchen & Bill Dvorzak
Chris & Wayne Loschinsky
Vivienne Nicely
Kathy & Tom Rimbey
Paula & Bill Wagoner
Lisa & Bruce Weaver

In Memory of Norman H. Bernstein
Mr. & Mrs. Garry Bloch
Elyse & Marty Eichner
Lori & Richard Guttman
I.F.C. Xtreme

In Memory of Grace Cunningham
Ms. Jean L. Rhodes

In Memory of Elizabeth M. Dorko
Mr. & Mrs. Thomas A. Butala

In Memory of Eugene P. Fabian
Art A., June H., & Zach M.
Chiavaroli
Mr. & Mrs. Russell T. Cope Jr.
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Michele Govora Sites
Christine M. Taylor
Charles & Mary Ann Tomayko

In Memory of Erma Fritz
Robert & Donna Dietsch
Carol & Lawrence Geisz
Norma Olson

In Memory of Selma Harlich
Walter & Rosemary Robison

In Memory of Veronica Lackner
Katherine & Wayne Schuetz

In Memory of John Lively
Fraternal Order of Police, Beaver
Valley Lodge No. 4

In Memory of Joseph Makray
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In Memory of Eileen Martin
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In Memory of Eleanor M. McAuliffe
Kathleen G. Burke-Koch
Financial Planning Advisors,
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Estate of Eleanor M. McAuliffe
Bob & Cindy Vaughn

In Memory of Helen Miller
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S.R. Snodgrass
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Pat Toth & Andy Waters
Steven & Terry Toth

In Memory of Kenneth Richard Sr.
Mr. Kenneth Richard

In Memory of Mary Alice Sichi
Carl & Joyce Brandtonies
Robert & Jozica Gorman
Mr. & Mrs. James Hassen
Ann & Bill McCormick
The Scotty Muir Family
Ms. Jennifer J. Patterson

In Memory of Carol Marie Spiller
Magenau
Steven Spiller

In Memory of Dorothy Annis Stewart
Kansas Association of Pi Beta Phi
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In Memory of Charles H. Stoner
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Paul & Jane Sylves
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In Memory of June I. Wallis
Doris Goehring & Family
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Murray & Marie McComas

In Memory of Florence Wilson
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In Memory of Joseph Zilich
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Nicholas & Dorothy Vay
Marilyn Wilson
Rose Marie Zilich

In Memory of Leonard Zyck

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Mildred & James Considine
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Judy Krause*

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*Bernard & Ethel Lazar Alzheimer
Research Fund*

Dale & Lynn Lazar
In Memory of Betsy Kanarek
In Memory of Tod Yoffie

Your contributions are greatly appreciated and help to support research and education in the area of Alzheimer's disease. You can remember or honor a loved one by using the envelope enclosed in this newsletter to send in your donation.

Topics at Noon Series

Noon-1 p.m.
ADRC Conference Room
4 South UPMC Montefiore
200 Lothrop Street
Pittsburgh, PA 15213

Thursday, November 15, 2007

“Memory Impairment in MCI: A
Cognitive Neuroscience Perspective”

David Wolk, MD
Assistant Professor of Neurology

Thursday, December 6, 2007

“Outreach and Recruitment of Minority
Elders for Health Research and
Programming: Systems Theory
and Community-Based Approaches”

Beth Sarles, MPH
ADRC Neuropsychology Program
Coordinator

Light refreshments will be served.
*Registration is not required. For more
information, call 412-692-2700.*

**December 31, 2007, Deadline for Special
Tax Benefits for IRA Gifts**

If you are at least 70 1/2 years old, you may be able to support Alzheimer's disease research with a direct transfer from your IRA or Roth IRA. Your gift of up to \$100,000 would not be counted as taxable income to you and it would be applied against your annual required minimum distribution. However, you must act quickly: This opportunity is scheduled to terminate at the end of 2007. Special rules apply. For more information, please contact Jim Olsen at 412-647-7781.



Doctor-Patient Communication is a Three-Way Street

by Jennifer Lingler, PhD



Jennifer Lingler, PhD, CRNP
Assistant Professor

In this issue of Pathways, the article titled “Caregivers: The Forgotten Patients” begins with a reminder of what a crucial role family members play in coordinating the health care of loved ones who are experiencing dementia. One important aspect of such care coordination

is facilitating communication between patients with dementia and their health care providers.

Symptoms like memory impairment and difficulty finding words make it challenging for some patients to reliably exchange information with clinicians. As you might imagine, a communication breakdown between patients and health care providers can have serious consequences. Research has linked poor doctor-patient communication to a variety

of negative outcomes, including lower overall health status. For patients with dementia, family caregivers play an important part in preventing communication breakdowns and their adverse consequences.

To learn more about the caregiver’s role in facilitating doctor-patient communication, Jennifer Lingler, PhD, and her colleagues have been conducting a study called ENACT: Evaluating the Nature of Alzheimer’s Communication Triads. Funded by the University of Pittsburgh Institute for Doctor-Patient Communication, this study involves interviewing patients and family members about doctor-patient communication and recording patients’ routine visits with their primary care providers.

The goal of ENACT is to determine which of the communication techniques used by caregivers are most effective. The techniques that are identified will be used to develop a set of best practices that can be taught to other caregivers. If you volunteered for ENACT and wish to learn more about the study findings, contact Lingler at 412-383-5214 or linglerj@pitt.edu.

Free Publications

Caregiver Guide: Tips for Caregivers of People with Alzheimer’s Disease
Alzheimer’s Disease Education and Referral Center (ADEAR), National Institute on Aging, National Institutes of Health: ADEAR publication
Order by calling 1-800-438-4380.

Steps to Success: Decisions about Help at Home for Alzheimer Caregivers

L.P. Gwyther, E.L. Ballard, and J.M. Pavon

Order by calling AARP at 1-888-687-2277 and asking for the Research Information Center.

Patient Assistance Programs for Prescription Medications: Obtaining Free or Discounted Medicines

Prescription drug prices are constantly on the rise and specialty medications, like those for Alzheimer's disease, can be priced out-of-reach for many people. Most pharmaceutical companies, however, sponsor patient assistance programs designed to provide free or discounted prescription medications for the uninsured and underinsured. The process of actually obtaining the medications can seem overwhelming, but the following are resources for application forms and suggestions for working with your physician to fill needed prescriptions.

Application Process:

The initial application can be time-consuming, but subsequent refill requests are usually much easier. Each pharmaceutical company has its own application and refill process. For example, you must apply to Forest's program for Namenda and Pfizer's program for Aricept separately. Applications must be signed by the patient and the doctor, and require original prescriptions as well as proof of income. By contacting the program's helpline directly (see below), you will find out exactly what must be included in your application packet. The company either sends a three-month supply of medication or a voucher to be used at a local pharmacy.

Working with Your Doctor:

Your physician wants you to take your medicine, so discuss these programs with your doctor if you cannot afford your medications. Some programs will only deliver your medicines to your doctor's office. It will be easiest for both parties if you devise a plan for getting paperwork signed and picking up your medicine in advance.

Alzheimer's Medications:

The following organizations provide individuals with information about how to navigate the sea of patient assistance programs.

| Medication | Medication Program Name | Phone Number |
|------------|--|----------------|
| Aricept | Aricept Assistance Program (Pfizer) | 1-800-226-2072 |
| Razadyne | Johnson & Johnson Patient Assistance Program | 1-800-652-6227 |
| Exelon | Novartis Patient Assistance Program | 1-800-277-2254 |
| Namenda | Forest Pharmaceuticals | 1-800-851-0758 |

This article is an exact reprint from the University of California, San Diego, ADC Name: Shiley-Marcos ADRC, Contact: Lisa Snyder, LCSW, 858-622-5800, lsnyder@ucsd.edu; Publication Date: Spring 2007.

Newly Funded Research Grants

New Investigator Research Grant from the Alzheimer's Association for Making Sense of Mild Cognitive Impairment: An Investigation of Patient and Family Perspectives

Jennifer Lingler, PhD
University of Pittsburgh

Investigator-Initiated Research Grant from the Alzheimer's Association for Measuring Suffering in Persons with Alzheimer's Disease

Richard Schulz, PhD
University of Pittsburgh



Alzheimer Outreach Center Can Help

Did you know that:

- African Americans may be at a higher risk of developing Alzheimer's disease (AD) than White Americans,
- There is a greater familial risk of AD in African Americans, and
- Genetic and environmental factors may work differently to cause AD in African Americans?*

The University of Pittsburgh Alzheimer Disease Research Center (ADRC) was established in 1985 by a grant from the National Institute on Aging. The Alzheimer Outreach Center (AOC) is the community satellite and outreach program of the ADRC. The AOC has been a part of the community since 1992.

The mission of the AOC is to increase awareness about AD in the African American community. The AOC provides:

- Evaluations of individuals with memory and thinking problems,**
- Diagnosis,
- Recommendations for treatment,
- Education and counseling for patients and families,
- Referrals to community resources,
- Support groups for caregivers, and
- Opportunities to participate in research studies.

Call or stop by the AOC for more information, community resources, or various research opportunities we offer.

**Alzheimer Outreach Center
Hill House Association
1835 Centre Avenue
Suite 230
Pittsburgh, PA 15219**

412-261-0742

* *Source: Alzheimer's Association, African Americans and Alzheimer's Disease: The Silent Epidemic. Available online at www.alz.org/national/documents/AA_ALZ.pdf.*

** *Memory evaluations are conducted by the ADRC at UPMC Montefiore in the Oakland neighborhood of Pittsburgh.*

Community Advisory Council Holds First Meeting

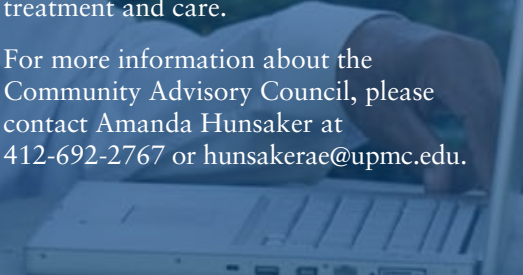
In May 2007, the ADRC convened the first meeting of its Community Advisory Council. The council's main objective is to encourage African Americans to participate in dementia research.

The mission of the Community Advisory Council is to work with the African American community to: facilitate involvement of older African Americans in state-of-the-art Alzheimer's disease and dementia research, provide venues for education and collaboration within the African American community regarding Alzheimer's disease and dementia, and serve as a sounding board for study results and upcoming research activities.

The council meets at the Hill House Association, a community service center in Pittsburgh's Hill District neighborhood and also where the ADRC's satellite office, the Alzheimer Outreach Center, is located. The council is made up of business and health professionals as well as individuals who have been personally affected by Alzheimer's disease.

During the first council meeting, several members emphasized the importance of providing accurate information on Alzheimer's disease to primary care physicians who serve the African American community. Physicians need to know what steps to take regarding diagnosis, treatment, and referral for dementia. To respond to this need, the ADRC is creating a packet of materials on Alzheimer's disease to share with primary care providers. The materials can be passed on to patients and family members as they make decisions about treatment and care.

For more information about the Community Advisory Council, please contact Amanda Hunsaker at 412-692-2767 or hunsakerae@upmc.edu.



Sweet to Study Behavioral Symptoms in AD



Robert A. Sweet, MD
Associate professor

Psychotic symptoms occur in 40 to 60 percent of patients with Alzheimer's disease (AD). These symptoms include hallucinations (hearing, seeing, or feeling things that are

not there), delusions (persistent false beliefs), and paranoia (an unfounded fear that people are planning to do you harm). Often these symptoms are distressing to the patients with AD and to their families, and current treatments have limited benefits.

For example, a recent large, multicenter study funded by the National Institute of Mental Health examined the effects of three antipsychotic medications versus placebos. The study found that patients receiving placebos were

more likely than patients receiving antipsychotic medications to stop treatment due to lack of benefit. On the other hand, individuals receiving any of the three antipsychotic medications were more likely to discontinue treatment than those in the placebo group due to side effects. The study concluded that the side effects of antipsychotic medications offset their effectiveness.

There is a clear need to find better forms of treatment for caring for or preventing psychotic symptoms in patients with AD. The first step toward this goal is trying to find out what causes these symptoms to occur.

Robert A. Sweet, associate professor of psychiatry and neurology at the University of Pittsburgh School of Medicine has received funding from the National Institutes of Health to study the role of genetics and other factors that may result in psychotic symptoms. His grant—Prediction of Psychosis in Alzheimer's Disease—has

been funded for a period of five years. In order to conduct the study, Sweet will analyze genetic and behavioral information that has been collected from participants at the ADRC.

The Alzheimer's Disease Genetics Initiative—funded by the National Institute on Aging and led by researchers at Columbia University—is a collaboration of several Alzheimer's Disease Centers across the United States that are looking to find the genes that may be associated with AD. Sweet has been asked to lead the psychiatric component of this national study, as collecting both genetic material and information about behavioral symptoms may provide valuable insights into the causes of psychotic symptoms.

Sweet and his study staff would like to thank you for your ongoing contribution to AD research and for helping the ADRC to study this important area of concern.

ADRC to Host New Seminar Series

The ADRC is pleased to present the Walter Allen Memorial Seminar Series, a community lecture series based at the Hill House Association, a comprehensive community service provider and facilitator in Pittsburgh's Hill District neighborhood.

Walter Allen was a prominent photographer from the Hill District who was diagnosed with Alzheimer's disease.

Lecture topics to date have included:

1. Identifying Memory Loss: What Can We Do?
2. Behavioral Symptoms in Alzheimer's Disease

For more information on this series, contact Amanda Hunsaker at 412-692-2767.

Join the Fight Against AD in the African American Community: Be a Healthy Volunteer

The Alzheimer Outreach Center (AOC) needs African Americans to participate in a research study as healthy volunteers. Healthy volunteers are people age 65 or older who are not experiencing serious problems with their memory or other thinking abilities.

Study participation involves:

- Medical/neurological examination,
- Paper-and-pencil testing, and
- Interviews with health professionals.

Volunteers are required to bring a study partner—a friend or relative who can accompany the volunteer and

answer questions about him or her. All information is kept confidential.

Healthy volunteers are very important in the fight against AD. By participating, you will help us gain a better understanding of the normal aging process and how AD is affecting the African American community. The results of your evaluation will be compared to other African Americans your age who have been diagnosed with AD. To learn if you qualify as a volunteer, please call the AOC at 412-261-0742.



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ADRC Mission

The overall objective of the ADRC is to study the pathophysiology (changes in the brain) of Alzheimer's disease (AD) with the aim of improving the reliability of diagnosis of AD and developing effective treatment strategies. The ADRC is funded by the National Institute on Aging, and, as part of the research program, provides a comprehensive outpatient evaluation, including medical, neurological, psychiatric, social, and cognitive assessments. A major focus of the ADRC is a commitment by individuals to participate in additional ADRC research studies. Individuals enrolled at the ADRC are encouraged to participate in additional studies in order to be followed by the center.

Need Help?

alzheimer's  association®

The Alzheimer's Association 24/7 Helpline provides reliable information and support to all who need it. Call the toll-free hotline anytime, day or night.

1-800-272-3900

