



*"Dedicated to improving the health, well-being  
and quality of life of patients and their  
caregivers."*

# NEWSLETTER

## ***Dear Friends of the Memory Disorders Clinic,***

For some of you this is the first receipt of our newsletter while others have received an earlier issue by email. This is our first issue in both print and email versions. This newsletter is made possible by generous grants from the National Institute on Aging, and gifts from private donors.

We see this as an opportunity to keep you abreast of the latest news and information about our practice and the diagnosis and care of memory loss and dementia. The newsletter will be sent out periodically.

For those of you who have email access and are receiving a print version please let us know your email address for future newsletters. If you want to be removed from our distribution list or know of someone who would like to be added, please contact Jennifer Klocinski at (215) 573-4634 or email her at [jennifer@mail.med.upenn.edu](mailto:jennifer@mail.med.upenn.edu).

### **Memory Disorders Clinic and Local Alzheimer's Association Chapter Team Up to Create First Patient Support Group in the Delaware Valley:**

We are very excited about our plans to organize a support group for early-stage dementia patients. Currently there are a variety of support groups designed for caregivers. However, patients have no similar group designed to address their thoughts and experiences living with a dementing illness. This project, done in conjunction with the Southeastern Pennsylvania Chapter of the Alzheimer's Association, will provide that forum for patients. Our plan is to have a series of meetings for early-stage patients with a concurrent session for family caregivers.

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If you think you might be interested in attending the patient support group please contact Jennifer Klocinski. She can be reached by phone (215 573-4634) or by email ([jennifer@mail.med.upenn.edu](mailto:jennifer@mail.med.upenn.edu)).

### **New Drug Trial Begins at the Memory Disorders Clinic**

Currently we are recruiting for a new clinical drug study. The goal of this trial is to see if the investigational drug (called CP-457, 920) can treat the symptoms of AD and to test the safety of the drug on Alzheimer's patients. Patients will receive the investigational drug (CP-457, 920), or Aricept (donepezil), or a placebo. Patients who enroll in this study need to be in between the ages of 55 and 90 with a diagnoses of mild to moderate Alzheimer's disease. They should not be on Aricept, Exelon, or Galantamine. If a patient is on one of these drugs, they should be willing to go off of it for 16 weeks. Patients need to be in good health with a close friend or loved one who can serve as a companion throughout the study. The study will last three months if you are currently not on Aricept, Exelon, or Galantamine and will last four months if you need to go off those medications. If you are interested in the study and would like further information please call the Clinical Research Coordinator, Kris Gravanda at 215-349-5903.



## Why I Went Into Dementia Care?

by Jason H.T. Karlawish, MD

*The following is the first in a series of articles about how the staff at the Memory Disorders Clinic became interested in dementia care.*

I came to dementia from the outside. I wasn't in the usual clinical fields: neurology or psychiatry. I didn't study basic sciences or brain scans. In the beginning, I wasn't even training to be a geriatrician. I was going to be a critical care physician.

In the autumn of 1994 my grandfather fell in his kitchen. His broken hip was an easy fix. But he died three months later. The events between his fall and his death were marked by a series of cascading complications. His mild Alzheimer's disease and the stress of the fall caused a delirium. One thing did not lead to another in a logical way. Instead, the chaos of human errors and complications bred a kind of firestorm until the December afternoon when we withdrew his intravenous nutrition and hydration and allowed him to die.

I had just finished my residency in internal medicine and was spending a year away from patient care. My hours were devoted to learning the scholarship in the field of bioethics. In those months, I began to cast a critical eye upon the basic habits and concepts I had well adopted over seven years of rigorous training. Simple questions began to bug me: What is aging? Is it a disease? Why is our health care system so very innovative and yet so very disorganized? I passed hours writing and reading on these topics, but after my grandfather got the best of care and yet the worst of care, I decided I had to change my plans. I dropped out of my critical care fellowship and became the lone fellow in the University of Chicago's geriatric medicine fellowship. Over the next two and one-half years I immersed myself in the theories of aging, disease, and the concepts of function and quality of life.

I started to focus on a vexing problem. Alzheimer's disease, chief among the dementias, progressively impairs a person's ability to make decisions, to state their preferences, and to make choices. While we all desire to produce safe and effective treatments, we need to do research and to measure the effects of

those treatments. But given the impairments I described, how do we do this research and measure the effects of treatments? The issues here include informed consent, scientific value and the choice of what is a clinically meaningful benefit of treatment. I knew dementia was my disease. I can think of no other disease that brings together all the challenges of medicine: uncertain causation, a challenging diagnosis, progressive functional impairments, terminal stages, the involvement of family, the need for long-term care, and impairments in decision making capacity. When I teach residents, I tell them that if you know dementia, you know medicine.

I am in dementia research and care because the science is fascinating, the questions profound and the stakes as high as can be. But this is a personal passion. When I meet an elderly man who affably struggles but fails to remember, I think of my grandfather. And when I meet a family member afraid of what the future will bring to their loved one whose mind is slowly failing, I think of his son, my father. And it is these memories that sustain me and give me the will to carry on in this field.

## MDC Website to Offer Lecture Series

<http://www.med.upenn.edu/ADC>

The latest website project under development is a five-part CME/CEU Lecture Series. CME stands for continuing medical education and CEU for continuing education unit. CME/CEU lectures are one way for healthcare providers to stay abreast of the latest developments and standard of care in their field of practice.

This web-based lecture series will be available to persons who are not healthcare professionals, trainees in the Physician and Nurse Practitioner Education Program, as well as healthcare professionals around the country for CME and CEU credits. Topics covered range from the diagnosis of dementia to bioethical issues. We are working with the Continuing Education Department in the School of Medicine in order to offer the CME and CEU credits starting in early 2002.



## What's New with Our Staff?

### ***Doctor Christopher Clark begins a sabbatical***

Starting July 1st, Doctor Christopher Clark, Director of the Memory Disorders Clinic, begins a year long sabbatical. His patients, their families and our staff will miss his presence in Ralston House.

His research during the year will take him West to the Oregon Health Sciences University. This sabbatical will focus on two connected areas of research. First, he will be looking at the biological differences that determine if Alzheimer's disease is expressed at an early age (65 to 75 years) as opposed to a late age (85 years or older). Physicians have found that the disease tends to be milder and progress more slowly in the oldest old. Dr. Clark's work will look at why this is the case and he will seek out biological markers to explain why this is so. He will be working with Dr. Jeffrey Kaye who runs the Oregon Brain Aging Study. This is a 12 year old study that examines the key to healthy aging in the oldest old.

The second focus of Dr. Clark's sabbatical will be on the differences in the experience of Alzheimer's disease in people with late age of onset (85 or more years) compared to an earlier age of onset (65-75 years) in terms of caregiving needs, disease management and end-of-life issues. If we can improve our understanding of the disease and the needs of this special population of patients we can help caregivers and clinicians provide better care.

### ***We wish a warm welcome to Doctor Marjorie Marenberg***

We are very fortunate that on July 23rd Marjorie Marenberg, MD, PhD, joined the Memory Disorders Clinic staff. She will be caring for Dr. Clark's patients on Monday afternoons with Marianne Watson, RN.

Dr. Marenberg received her doctorate degree in epidemiology in 1992 and her medical degree in 1996, both from Yale University. She graduated from the Fellowship Program in Geriatric Medicine at the University of Pennsylvania last July and joined the Geriatric Medicine faculty in the fall. Her research interests include the role of cardiovascular risk

factors in cognitive impairment, race, and gender differences in subclinical atherosclerosis in the elderly.

### ***We bid a fond farewell to our Clinical Research Coordinator, Aba Delsignore Moser***

Aba came to us from Ticino, Switzerland and will be returning home. She has been a wonderful asset to our team at the Memory Disorders clinic and will be deeply missed.

*Dear patients and families,*

*After working for two and one half years at the Memory Disorders Clinic, it is now time for me to go back home and continue my career there. It's hard to say goodbye because I had such an enriching time working with you. Thank you to the patients and families who made our research projects possible.*

*Kris Gravanda is going to take over my position starting July 1, 2001. She is wonderful and I can assure all the research patients that you will be in good hands!*

*I will miss you all,*

*Aba Delsignore Moser*

### ***We are happy to introduce our new Clinical Research Coordinator, Kris Gravanda...***

We extend a warm welcome to Kris Gravanda. She is the new Clinical Research Coordinator at the Memory Disorders Clinic. Kris received her BA in Sociology and Gerontology from Case Western Reserve University. Prior to her arrival she interned at Myers Research Center at Menorah Park Center for the Aging in Cleveland, Ohio. Kris has spent the month of June working with Aba to ensure a smooth transition. She is looking forward to meeting you all personally and getting the chance to work with you.



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## Memory Walk 2001

The Alzheimer's Association annual Memory Walk will be held on the following dates:

Philadelphia:

Saturday, September 22nd at Memorial Hall

Lehigh Valley:

Saturday, October 6th at Trexler Game Preserve

Berks County:

Saturday, October 13th at Gring's Mill

The walk funds vital programs offered by local Chapters of the Alzheimer's Association. If you have any questions about the Memory Walk or would like to form a team contact the Alzheimer's Association at 1-800-559-0404. As usual, the Memory Disorders Clinic will have a team at the Philadelphia Memory Walk.

## Summertime Tip:

Summer is a time of year when we often enjoy the out-of-doors with backyard barbecues and family vacations. Family outings can be fun but also hectic and may be held in a place that is unfamiliar to your loved one with memory difficulties. Therefore, summer is also a time of year when people with memory problems may wander and get lost. One important way you can insure your loved one's safety is by registering him or her with the Alzheimer's Association's Safe Return Program. For more information about this program you can contact our social worker, Mirna Negron at (215) 349-8768 or contact the Alzheimer's Association at (888) 572-8566 or register on-line at <https://www.alz.org/caregiver/programs/safereturn.htm>.

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## Memory Disorders Clinic

University of Pennsylvania

3615 Chestnut St.

Philadelphia, PA 19104