Dear Friends of the ADRC,

The staff and faculty of the University of Pittsburgh Alzheimer Disease Research Center (ADRC) have been busy preparing a progress report for the National Institute on Aging (NIA; part of the National Institutes of Health) describing the recent accomplishments of and work done here at the ADRC. In doing so, we had the opportunity to reflect on some of the center’s most important contributions to the field of Alzheimer’s disease (AD) research. It’s impossible to think about those contributions without recognizing that the single most important reason for our achievements has been the partnership we have with our research volunteers. Did you know that we have one of the largest groups of research participants among all of the NIA-funded AD centers across the country? Research data from our participants have contributed to hundreds of scientific publications over the years. The willingness of research participants to participate in not only the initial ADRC evaluation but also subsequent research studies demonstrates the remarkable, unselfish willingness of our patients and families to donate their time to all aspects of AD research. This altruistic spirit also is evident in our participants’ responsiveness to our recent efforts to increase participation in the center’s brain donation program. Over the past two years, the number of patients and families who have expressed provisional interest in brain donation has tripled, and the number of actual autopsies leading to brain tissue being available for critical research projects has increased accordingly. The value of brain donation to the future of AD research simply cannot be emphasized enough.

A gift of this sort can contribute to ongoing studies for more than a decade, creating a very real legacy of contributions to AD research. For example, autopsy donations from the 1980s contributed directly to the development of brain amyloid imaging in 2002.

Moving forward, ADRC participants will continue to receive information about opportunities to volunteer, if eligible, for upcoming studies, some of which focus on brain scanning and others that focus on testing new treatments. We anticipate that future studies will begin to focus on the very earliest signs of self-detected memory loss. For that reason, we have great need for participation by people who believe they have no memory problems as well as people who aren’t completely sure if they have a memory problem. Many people don’t realize that research volunteers with no or minimal memory complaints are just as valuable to our research endeavors as those with clear memory problems. As always, we ask for your help in referring any appropriate volunteers to us (or in volunteering yourself!).

We thank you once again for your contributions to AD research, and we look forward to seeing you at your next annual visit.

Sincerely,
William E. Klunk, MD, PhD, Codirector

This series will address the following questions:
1. What are clinical trials?
2. What are the benefits of volunteering for a clinical trial?
3. Why are placebos important in clinical trials?
4. What is informed consent?
5. What steps does a person go through to enroll in a clinical trial?
6. What happens during a clinical trial?

Continued on page 2
The Benefits of Volunteering for a Clinical Trial

By being part of a clinical trial, volunteers can help to move research forward.

Without clinical trials, there can be no better treatments, no prevention, and no cure for Alzheimer’s disease. Scientists work constantly to find better ways to treat diseases, but improved treatments can never become a reality without testing in clinical trials with human volunteers.

Volunteers may:
- help others, including future generations, who may be at risk for developing Alzheimer’s disease;
- receive regular monitoring by Alzheimer’s health care professionals;
- gain access to potential treatments before they are widely available;
- learn more about the disease from experts who are on the cutting edge of research; and
- get information about additional resources and support groups.

For information about clinical trials that are currently enrolling participants at the Alzheimer Disease Research Center, refer to pages 10 and 11 of this issue of Pathways.

(Information for this article was obtained from the Alzheimer’s Disease Education and Referral Center fact sheet, “Participating in Alzheimer’s Disease Clinical Trials and Studies”.)

Tips for Traveling with a Person with Dementia

By Thomas Baumgartner Jr., MPH, MSW, LSW

The warm weather has arrived, and for many families this means planning a vacation. Caregivers of persons with dementia often will ask if traveling with their loved ones is possible, whether it be for a whole week away to a distant location or even just a long weekend at a destination that may be a few hours away by car.

Regardless of the distance being traveled, planning a vacation always requires time and thought. When preparing to travel with someone with a dementia disorder, like Alzheimer’s disease, there are additional considerations that need to be taken into account ahead of time. For instance, the patient’s level of impairment will help the caregiver to determine what is realistic in terms of the vacation’s length, destination, and mode of transportation and whether an additional traveling companion may help to make the vacation more manageable.

If you are thinking about summer travel, the following suggestions may be helpful as you begin to plan.

1. Speak with your loved one’s family doctor to determine if he or she thinks it is a good idea to travel. Persons with dementia can experience symptoms related to mood, such as anxiety, depression, agitation, and paranoia. Because traveling can sometimes make these symptoms more pronounced, the doctor may have medication recommendations to consider while traveling.

2. Nonstop flights are preferable when traveling by airplane. If possible, inform airline and security personnel that you are traveling with a person who has dementia. Carry all of your loved one’s pertinent papers and identification yourself. Bring some type of activity (e.g., puzzles, word searches) for him or her to do while waiting to board and while the flight is in progress. Provide others with important contact information while you are away, such as your cell phone number, hotel information, and flight itinerary.

3. If traveling by car, bring an activity for your loved one, take rest breaks as needed, and pull over if he or she becomes upset at any point.

4. Keep in mind that your loved one’s familiar routine will become disrupted by placing him or her in a new environment. It is important to keep his or her schedule as familiar as possible, such as when to eat or take medications. Convey a tone of voice and body language that are comforting to the patient as the vacation proceeds. Plan enough time into the itinerary so that you do not feel rushed.

5. Obtain an identification necklace or bracelet (e.g., MedicAlert + Alzheimer’s Association Safe Return program) in the event that your loved one wanders and becomes lost. Create and hand out business card-sized cards that explain that the person you are traveling with has memory or thinking problems.

6. If you are staying at a hotel, inform the staff that you are traveling with someone with dementia. Request a room that is in a quieter part of the hotel. Consider obtaining a portable door alarm device to prevent wandering. Become well aware of the exits and escape routes in the event of a fire or other emergency.

7. Should your loved one require medical attention while on vacation, remember to carry a complete list of his or her medicines and medical conditions to give to the treating physician.

For more tips related to traveling with a dementia patient, please visit the Alzheimer’s Association Web site at www.alz.org/care/alzheimers-dementia-and-traveling.asp.

We at the Alzheimer Disease Research Center wish all of you a wonderful summer and safe travels.
Recent estimates suggest that one in three Americans will have dementia when they reach the end of life. For many individuals, this striking statistic is a sobering reminder of the need to plan ahead to ensure that one’s views and wishes are known to those who will be overseeing one’s care at the end of life.

The POLST form is a document designed to help health care professionals honor the treatment wishes of patients who are seriously ill or have an end-stage medical condition or advanced frailty. Patients with dementia or their caregivers should talk to their health care professionals about the value a POLST form can provide as one approaches the end of life.

The POLST form is used in states across the country and within all levels of care, from acute care hospitals to skilled nursing and long-term care to hospice. It is a brightly colored form that is easily recognized and accompanies a patient across care settings.

When patient treatment preferences are documented on the POLST form and signed by the patient or medical decision maker and a doctor or nurse practitioner, they become medical orders to be followed.

Ideally, the best time to have the conversation is when a patient is able to participate. All patients with early dementia should be engaged in an advance care planning (ACP) conversation and their goals of care elicited. The patient should be encouraged to complete an advance directive, name a health care surrogate, and discuss wishes for future medical care with the surrogate. An online resource that is useful for this purpose can be found at www.prepareforyourcare.com.

When a patient is considered to be approaching moderate dementia, a discussion of POLST is appropriate, and it is useful for the surrogate to participate. The discussion can consider care from the present time through disease progression to end stage. It should be clear to the patient that once the POLST form is completed, it can be changed or revoked at any time.

It is never wise to assume that a patient with dementia is unable to engage in ACP discussions. At all stages, try to discern what is most important in terms of care choices. Help to ensure that your own or your loved one’s preferences are respected at the end of life.

If you are looking for further information on POLST, talk to your health care professional or go to www.aging.pitt.edu/professionals/resources-polst.htm.

Additionally, ADRC is partnering with Highmark Inc. and the Alzheimer’s Association in a new effort to help individuals in our region to plan ahead to help ensure that their preferences are met at the end of life.

As the table below demonstrates, there are differences between a POLST form and an advance directive.

<table>
<thead>
<tr>
<th><strong>ADVANCE DIRECTIVE</strong></th>
<th><strong>POLST</strong></th>
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<tbody>
<tr>
<td><strong>POPULATION</strong></td>
<td>All adults</td>
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<tr>
<td><strong>TIME FRAME</strong></td>
<td>Future care/future conditions</td>
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<tr>
<td><strong>WHO COMPLETES FORM</strong></td>
<td>Individuals/patients</td>
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<tr>
<td><strong>WHERE COMPLETED</strong></td>
<td>Any setting, not necessarily medical</td>
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<tr>
<td><strong>RESULTING PRODUCT</strong></td>
<td>Surrogate appointment and statement of preferences</td>
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<tr>
<td><strong>SURROGATE ROLE</strong></td>
<td>Cannot do</td>
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<tr>
<td><strong>PORTABILITY</strong></td>
<td>Patient/family responsibility</td>
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<td><strong>PERIODIC REVIEW</strong></td>
<td>Patient/family responsibility</td>
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Segments of this article are based on the webinar The Role of POLST in the Care of People with Dementia by Kenneth Brummel-Smith, MD, Charlotte Edwards Maguire, MD, Chair and professor of geriatrics, Florida State University College of Medicine.
While genes are important, the story is not that clear cut. To address this complicated question, scientists have focused on the genetics involved in the two major forms of AD: early onset and late onset.

EARLY ONSET ALZHEIMER’S DISEASE
Many people think of Alzheimer’s as a disease of old age. While getting older does increase the risk of developing the disease, there are some very rare cases that manifest years before a person is eligible for a senior citizen discount. This early onset form of AD generally affects people between the ages of 40 and 60 and is...
passed on through generations by mistakes, known as mutations, in the DNA code that makes up our genes. In the 1980s and 1990s, scientists began looking at families with early onset AD to determine what parts of the inherited genome were responsible for causing this devastating illness. They found that all affected family members shared the same copy of a mutated gene, which resulted in the production of unusually large amounts of a protein known as beta-amyloid.

Large amounts of beta-amyloid protein clump together in the brain, forming plaques, a hallmark of AD. These clumps of beta-amyloid protein set off an array of other internal changes, causing the formation of neurofibrillary tangles—the second classic indicator of the disease. Neurofibrillary tangles build up inside brain cells and eventually kill them. As the brain cells die, symptoms of the disease develop.

A child whose parent carries a copy of the early onset genetic mutation has a 50/50 chance of inheriting that mutated gene. If the mutation is inherited, there is nearly a 100 percent chance of developing AD.

Scientists have identified a number of single gene mutations, each of which is passed on through families, that can lead to the creation of too much toxic beta-amyloid protein in the brain. While different mutations affect different parts of the beta-amyloid production process, the end result is the same: harmful protein accumulation that eventually kills brain cells.

Not all cases of early onset AD have a known cause, suggesting there are still some gene mutations scientists have yet to discover.

**LATE-ONSET ALZHEIMER’S DISEASE**

While Alzheimer’s disease can occur early on in life, the vast majority of cases start later, after the age of 65. Unlike early onset, the causes of late-onset AD are not entirely clear. There does not seem to be a single gene mutation that is directly responsible for developing the disease. Rather, a combination of genetic and environmental factors likely influences the risk.

One genetic risk factor involves the apolipoprotein E (APOE) allele. An allele is a gene that can take on a number of different forms, much like ice cream can have a variety of different flavors. In the case of APOE, there are three major forms that can be inherited: APOE-ε2, APOE-ε3, and APOE-ε4.

APOE-ε3 is the most common form and does not increase or decrease the risk of developing the disease. APOE-ε2 is a relatively uncommon form of the APOE allele that is thought to provide some form of resistance against developing the disease. If an individual with the APOE-ε2 allele does develop AD, it is normally much later in life than someone with the APOE-ε4 form.

People who have the APOE-ε4 allele have an increased risk of developing AD. This allele appears in approximately 40 percent of all late-onset cases.

Every person has two copies of the APOE allele, one from each parent. For example, someone could inherit one copy of the APOE-ε3 allele from their mother and one copy of the APOE-ε4 allele from their father. If both of the alleles are the APOE-ε4 form, the risk of developing AD is higher than if only one copy is inherited.

It is not yet fully understood why inheriting the APOE-ε4 allele increases the risk of developing late-onset AD. While 20–30 percent of the population carries the APOE-ε4 allele, having it does not guarantee that someone will develop AD; it only means that the risk is increased.

AD impacts millions of people around the world. As scientists uncover more information about how genes factor into this complicated disease, our understanding of its causes exponentially increases.
Alzheimer Disease Research Center (ADRC) staff have continued to keep a presence in the community to raise awareness of and disseminate information about Alzheimer’s disease despite the rough winter season that thankfully is now behind us. Recent events include presentations at Broadview Manor, Versailles Apartments, John Fraser Hall, and Port Vue Apartments. The ADRC also was an exhibitor at the Center for Health Equity’s annual Take a Health Professional to the People Day.

The spring 2014 Walter Allen Memorial Seminar Series was held on May 8, 2014, at the Hill House Association Kaufmann Center auditorium. Dr. Patrick A. Griffith, professor of clinical medicine and chief of neurology at Morehouse School of Medicine in Atlanta, Ga., gave an impassioned lecture titled “Are African Americans a Part of the Alzheimer’s Disease Story?” We are pleased that the event was attended by many enthusiastic community members and health professionals.

The ADRC is excited to announce a new partnership with the Vintage senior center. ADRC investigators are taking part in a brain health education series titled A Series to Remember: Presentations with Experts on Brain Health, Memory, and Aging. The inaugural presentation took place on May 30 with Dr. Jason Flatt, a postdoctoral fellow in neuroepidemiology and clinical and translational science at the University of Pittsburgh. Flatt spoke on “How People Are Good for Your Brain.” The next lecture is set for Friday, June 27, 2014, at 11 a.m. and will feature Dr. Kirk Erickson, associate professor in the Department of Psychology at the University of Pittsburgh. Erickson will speak about the beneficial effects of fitness and exercise on the brain. The Series to Remember presentations will take place at the Vintage senior center, located at 401 North Highland Avenue, Pittsburgh, PA 15206.

If you would like information about upcoming seminars and/or support groups, please contact Marita Garrett at 412-692-2722 or garrettm@upmc.edu.

At the Alzheimer Disease Research Center University of Virginia satellite, we have been focusing on partnerships, specifically with the local Alzheimer’s Association chapter in central and western Virginia. In May 2014, Carol Manning, PhD, clinical associate professor at the University of Virginia School of Nursing, and Ishan Williams, PhD, assistant professor of nursing and a Roberts scholar at the University of Virginia, were guest speakers at a workshop titled Women at the Epicenter of Alzheimer’s. Manning spoke on the differences between normal aging and Alzheimer’s disease, including diagnostic procedures and other dementias. Williams spoke about the challenges of the caregiving journey for diverse populations. This educational workshop was attended by aging services providers, direct care workers, and family caregivers. We find these opportunities to be enriching and a way to give back to community members who also may be participants in our satellite center.
In Memoriam

The University of Pittsburgh Alzheimer Disease Research Center thanks the following individuals and organizations for their generous donations received between October 23, 2013, and April 29, 2014.

In Memory of John David Arbuckle
Alice Randall
Ruth Vore

In Memory of Joseph Barber
Wendy Black

In Memory of Frances Barnes
Raymond and Nancy Cray

In Memory of Sandra Briggs
Barbara Demcisak
Donald and Anna Lee Earnest
Darlene Hadix
Carol Smith
Washington Health System Maintenance Department
Janet Zink

In Memory of Joy Brocklebank
Theresa Mangini and Melissa Snyder

In Memory of Mary Bronzini
Joseph DiMaio

In Memory of Dr. Milton W. Burkhart
American Board of Psychiatry and Neurology, Inc.
Carl and Elaine Bartelt
James and Carolyn Belz
John and Donna Bodenstein
Arthur and Carol Byers
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Joseph and Patricia Quigley
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Lorraine Tough
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Jeffrey and Patricia Caringola

In Memory of Thelma Carnahan
Susan Benton

In Memory of Marion Weis Cohen
Mary Ann Wilner

In Memory of Frank Demma
Jeffrey and Daneen Boehme and Family
Betty Charles
Betty Lamb
Phillip M. Vito and Family

In Memory of Helen Fornadley
Wendy Black

In Memory of Sarah Jane Gleeson
Roberta Marie Churilla

In Memory of Betty Gloekler
Louisa Rudolph

In Memory of John Hartman
Betty Jane McGonigle

In Memory of Jean Voltz Herman
Douglas and Sandra Pierre
Edward and Marjorie Sebring

In Memory of Joseph F. Hirko
Mary Kay Krause

In Memory of Irmgard Hofrichter
Coldwell Banker Real Estate

In Memory of Marilyn Jacobs
Blaire and P. Gayle Fisher

In Memory of Michael Kostek
Estate of Michael Kostek

In Memory of Jeannette F. Kraus
Rose and Fred Balestra
Bob and Monica Hancharek
John Kraus
Sam and Regina Lecria
Julia Paci and Family

In Memory of John Manes
Betty Manes

In Memory of Charles A. Miller Jr.
Peter and Twila Miller

In Memory of Albina Elizabeth Mutschler
William and Diana Anlauf
Margaret Baumgartner

In Memory of Betty Joan Natcher
Elaine Presnar
Friends at the Pennsylvania Rail Car Co.

In Memory of McKay Palmo
Scott and Belinda Hunter
Brenda Palmo

In Memory of Mary Pratte
Cathleen Borkovic
Brian and Carolyn Burke
Paul and Jennifer Courtney
Raymond and Rosemary DeCook
David and Betty Lee Forrester
Regina and Steven Freschi  
Linda Jennings  
Chelsea Mason  
Roy and Geraldine Mizelle  
Margaret Murtha and Janice Chuncnick  
Patrick and Catherine Rainville  
Robert and Marlene Schaub  
James and Rebecca Smedley  
Charlie and Patricia Winlow  

**In Memory of Henry W. Riebel**  
Patricia Riebel and Margaret Hilf  

**In Memory of Alan Romatowski**  
Mary Criscenti  
Robert and Judith Greenberger  
Ronald and Ernestine Jeroski  
Arthur and Gloria Pollock  

**In Memory of Peggy Rosenberger**  
Scott and Belinda Hunter  

**In Memory of Marilyn Schaefer**  
The Backer Family  
The Otti Family  

**In Memory of Wayne Schuetz**  
Roberta Marie Churilla  
Katherine Schuetz  

**In Memory of Richard Seckinger**  
William Thomas  

**In Memory of Rita Shaffalo**  
Dale and Lynn Lazar  

**In Memory of Wayne Shoemaker**  
Doris Shoemaker  

**In Memory of Steven Gregory Sinkevich**  
Lucinda Sinkevich  
Sylvan, Inc.  

**In Memory of William J. Sisley**  
Virginia Bartolomeo  
Timothy and Carol Kyle  

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**In Memory of Paul Souzer**  
Gretchen Sloppy  

**In Memory of Robert and Jane Stonerod**  
Marsha Lauterbach VanKirk  

**In Memory of Donald Streams**  
The Blairsville Monday Music Club  
Oliver and Susan Cunkelman  
Joyce Diamondstone and Family  
Edward and Sherrill Kuckuck  
John and Ruth Smith  
The United Presbyterian Church Choir of Blairsville  

**In Memory of Anne B. Townsend**  
Raymond and Nancy Cray  

**In Memory of James F. Turk**  
The Employees of PNC Wealth Management  

**In Memory of Mary Lou Underkoffler**  
Dennis Crouch  
Richard DiSalle  
Engle’s Holiday Harbor, Inc.  
The Jolly Girls  
Richard and Judy Lounder  
Jason Mazza  
John Mazza  
Madaline Mazza  
Robert Mazza  
Thomas and Mary Shell  
Walter and Eileen Van Dyke  

**In Honor of Joy Brocklebank**  
Dana Sutton and Kathryn Sinkovich  

**In Honor of Elizabeth T. Harvey**  
Joan Harvey and Michael Lotze  

**In Honor of Esther Palkovitz’s 90th Birthday**  
Dale and Lynn Lazar  

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**2013 Thompson High School Volleyball Team Annual Fall Alzheimer’s Awareness Fundraiser**  
John and Robyn Bohlman  
Mary Jo Grover  
James and Catherine Stallard  
Thompson Public School District #61  

**Research Donations**  
Valentino and Carol Buttignol  
Eleanor Campbell  
Nancy T. and William S. Conover II Fund  
Anna Marie Criss  
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Eric C. Olson  
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Gary Eaborn  
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Sean Flanigan  
Britney Fontecchio  
James Gianmarco  
Christine Gibson  
Karen Goldman  
Kathy Hardy  
Heidi Hartge  
Kurt Hundertmark
Use Your Legacy to Protect the Future of ADRC Research

If supporting Alzheimer’s disease research is important to you, you may want to consider including the Alzheimer Disease Research Center in your estate plans. A few moments of planning now can enable you to have a significant impact on our quest to better understand and treat Alzheimer’s disease and related conditions. Making a bequest costs you nothing during your lifetime but can dramatically shape the future for our patients, their families, and their communities.

It’s easy to include language in your will stating that you would like to donate to Alzheimer’s disease research. You can even indicate how you’d like your gift to be used. Existing wills can be updated with something known as a codicil, a simple document that adds a new bequest while reaffirming the other terms of your will. If you’d like to know more about the process or notify us of your intentions, contact Jim Olsen, major gifts officer for neurology, neurosurgery, and psychiatry in the Medical and Health Sciences Foundation, at 412-647-7781 or ojim@pmhsf.org. He can answer your questions and help to make sure your wishes are honored.

The Alzheimer’s Association 24-hour helpline provides reliable information and support to all who need it. Call the toll-free hotline anytime, day or night, at 1-800-272-3900.

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.
Get involved! We are in constant need of participants for several research studies and invite anyone with interest to call the ADRC at 412-692-2721 or e-mail oakleym@upmc.edu.

Medication Study for the Treatment of Agitation in Moderate to Severe Alzheimer’s Disease

**DESCRIPTION**
The purpose of this study is to determine whether an investigational medication (ELND005) is effective for reducing behaviors in people with moderate to severe Alzheimer’s disease who have agitation/aggression.

**STUDY LENGTH**
12 weeks

**STUDY REQUIREMENTS**
- 50–95 years of age
- A diagnosis of moderate to severe Alzheimer’s disease
- A study partner who will accompany you to all study visits

Expedition 3 Clinical Trial

**DESCRIPTION**
This study will test the idea that the investigational medication solanezumab will slow the cognitive and functional decline of Alzheimer’s disease (AD) in participants with mild AD.

**STUDY LENGTH**
Approximately 18 months

**STUDY REQUIREMENTS**
- 55–90 years of age
- A diagnosis of mild Alzheimer’s disease
- A study partner who will accompany you to all study visits

**CONTACT**
MaryAnn Oakley at 412-692-2721 or oakleym@upmc.edu
AMBAR Study

DESCRIPTION
The purpose of this study is to determine whether short-term followed by long-term low-volume plasma exchange (a process of blood filtering) is able to modify Alzheimer’s disease patients’ cognitive, functional, and behavioral symptoms.

STUDY LENGTH
14 months (six weekly plasmapheresis sessions followed by 12 monthly plasmapheresis sessions)

STUDY REQUIREMENTS
• 55–85 years of age
• A diagnosis of mild Alzheimer’s disease
• A study partner who will accompany you to all study visits

Learning New Fact Knowledge through Reinforcement

DESCRIPTION
This is a behavioral study investigating how people acquire factual knowledge using feedback and repetition. The data gathered through this project are expected to enhance investigators’ understanding of how different memory systems interact and how people might change their strategies to learn optimally. Participants will be asked to work through a series of talks on a computer (no computer knowledge is necessary).

STUDY REQUIREMENTS
• Participants with a diagnosis of Alzheimer’s disease
• ADRC control participants

The RECALL (Retaining Cognition while Avoiding Late-life Depression) Study

DESCRIPTION
This research project will test whether problem solving therapy (PST) is successful in preventing major depression for those living with mild cognitive impairment. It also will examine the effect of modest exercise on mood.

STUDY LENGTH
8–12 weeks of PST sessions and follow-up visits at three-month intervals for 12 months

STUDY REQUIREMENTS
• 60 years of age or older with a diagnosis of mild cognitive impairment

Family Caregiver Video Study

DESCRIPTION
The goal of this study is to learn how family caregivers deal with dementia-related behavior and how they respond to suggestions for handling these situations at home. Participants will be asked to wear a video device at home to capture daily interactions with their family member who has dementia.

STUDY REQUIREMENTS
• Person age 50 or older with moderate to severe dementia
• Willingness to engage in all study activities at home and by phone
• Family caregiver age 21 or older who provides care to a person with moderate to severe dementia
What resources are available for children and adolescents whose parents have early onset dementia?

A: While a diagnosis of Alzheimer’s disease (AD) or another type of dementia is difficult for any family, such news may be especially distressing for a child or young adult whose parent develops the condition, as is often the case in early onset Alzheimer’s. The labels of early or younger-onset AD, which account for about 4 percent of all cases of AD, are given when people develop the condition before the age of 65, often while in their 40s or 50s. Because this is a condition of much interest in the research community, the University of Pittsburgh Alzheimer Disease Research Center (ADRC) sees many individuals in this situation, and our social workers and other clinicians work hard to equip families with practical ways of helping children and adolescents to cope with its challenges. While there are certain rules of thumb that we abide by, it always is crucial to consider the developmental stage of the child as one identifies a plan for offering information and support that will be most helpful. The Alzheimer’s Association stresses that children may express a wide gamut of emotions in response to an affected parent. These include sadness, fear, confusion, resentment, and embarrassment and often can be expressed in ways that may not be easy to recognize, like complaints of physical ailments such as stomachaches and headaches.

This spring, the ADRC hosted Mariah Streck, a senior-level nursing student who completed her community health nursing rotation at the center. Because of her experience as a child of a parent with early onset Alzheimer’s, Streck was keenly aware of the need to provide high-quality and easily accessible services for children and teens in that situation. With support from the ADRC and the Greater Pennsylvania Chapter of the Alzheimer’s Association, Streck took action and formed a new online support group specifically for adolescents living with a parent who has dementia. Called Growing Up Purple, this group is available to those ages 16–25 and uses video chat and message boards to connect teens and young adults to others in a similar situation with the support of a trained facilitator. For information about the group’s next virtual meeting, send an e-mail to growinguppurple@alz.org.