Dear Friends of the ADRC,

Greetings! With fall under way and winter approaching, it is a busy time at the Alzheimer Disease Research Center (ADRC), and I am pleased to provide you with some highlights of our recent activities.

While ADRC faculty and staff members are involved in numerous dementia care and research initiatives at the local, regional, national, and even global levels, we are especially pleased by the progress that is being made in the Commonwealth of Pennsylvania. In February of this year, Governor Tom Corbett signed an executive order creating an Alzheimer’s disease (AD) state planning committee to address the growing threat of AD in Pennsylvania. Chaired by Secretary of Aging Brian Duke, this committee consists of 26 people representing various agencies and organizations as well as people directly affected by the disease. UPMC Endowed Professor of Geriatric Psychiatry and ADRC collaborator Charles F. Reynolds III, MD, is serving on the state planning committee and chairing a work group on prevention and outreach. On September 17, several of us from the ADRC participated in one of multiple public meetings held across the state to provide input and direction to Duke and the committee. It was an informative event and energizing to see so many people express their commitment to fighting AD. According to the governor’s office, the state’s comprehensive AD plan will be developed by February of 2014. We eagerly await its unveiling and encourage you to keep an eye out for news on this early in the coming year.

Back at the ADRC, we are gearing up to launch a new clinical trial, nicknamed Expedition 3. You can learn more about clinical trials in general and Expedition 3 in particular on pages 2 and 3 of this edition of Pathways. While Expedition 3 is designed for individuals who have been diagnosed with AD, do keep in mind that we are always in need of healthy control volunteers age 65 years and older as well as older adults who are experiencing mild memory loss. Please consider referring a friend or family member to volunteer for research at the ADRC.

On behalf of the ADRC faculty and staff, I wish you all the best as 2013 comes to a close.

Sincerely,
Oscar L. Lopez, MD, Director

Back at the ADRC, we are gearing up to launch a new clinical trial, nicknamed Expedition 3. See page 3 to learn more about this exciting trial.

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?

This is the first in a series of articles about Alzheimer’s disease (AD) research and participation in clinical trials.
What Are CLINICAL Trials?

Clinical research is medical research involving people. Clinical trials test possible interventions to diagnose, treat, prevent, and one day cure a disease.

There are four well-defined phases through which clinical trials advance:

- **Phase I:** Researchers test a new drug or treatment in a small group of people for the first time to evaluate its safety, determine a safe dosage range, and identify side effects.
- **Phase II:** The drug or treatment is given to a larger group of people to see if it is effective and to further evaluate its safety.
- **Phase III:** The drug or treatment is given to large groups of people to confirm its effectiveness, monitor its side effects, compare it to commonly used treatments, and collect information that will allow the drug or treatment to be used safely.
- **Phase IV:** Studies are done after the drug or treatment has been marketed to gather information on the drug’s effect in various populations and any side effects associated with long-term use.

While most people associate clinical trials with new medications (drugs), clinical trials can be conducted for many different types of interventions, including medical devices, prevention methods, and diet and lifestyle changes.

There are many drugs currently in clinical trials for AD and more awaiting U.S. Food and Drug Administration (FDA) approval to begin human trials. Prior to approval by FDA for human testing, investigational drugs go through laboratory analysis in test tubes, in tissue cultures, and then in laboratory animals to test their safety and efficacy. If results are favorable, then FDA gives approval for the intervention or treatment to be tested in humans.

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.)

Brain Donation Program

The Alzheimer Disease Research Center (ADRC) offers a brain donation program to center participants. ADRC patients and families are routinely asked to consider participating in this program.

A brain autopsy allows for a final confirmation or clarification of an individual’s diagnosis. For researchers, it provides a key puzzle piece that allows them to see exactly what changes in the brain were causing the symptoms observed during the illness. This is crucial if we are to truly understand Alzheimer’s disease (AD) and other brain disorders. At our center, this information is passed along directly to families in the form of a full report, which is mailed to them once the brain autopsy is complete.

Many families find that getting diagnostic confirmation provides closure to or resolution of the caregiving experience.

In addition to studying the brains of individuals with a diagnosis of AD or another form of dementia, researchers are interested in learning more about changes that occur in the healthy brains of older adults. Studying these brains will help them to identify exactly which changes are related to disease and which are related to aging.

Brain autopsies of persons with and without dementia contribute greatly to medical research. For more information about our brain donation program, please call the ADRC at 412-692-2700.
The Alzheimer Disease Research Center (ADRC) is currently recruiting individuals who have been diagnosed with mild Alzheimer’s disease (AD) for the Expedition 3 trial.

The Expedition 3 study will test the hypothesis that the investigational compound solanezumab will slow the cognitive and functional decline of individuals with AD as compared to a placebo in participants with mild AD. Solanezumab is an antibody being developed as a passive immunization therapy for AD. Solanezumab binds or sticks selectively to certain forms of the amyloid-beta (Aβ) peptide in the brain. Previous clinical research trials with this compound demonstrated a slowing of cognitive decline in patients with mild AD, according to researchers.

This is a Phase III clinical trial in which participants will be randomized on a 1:1 ratio (50 percent will receive solanezumab and 50 percent will receive a placebo) and will receive either solanezumab or a placebo by intravenous (IV) infusion once every four weeks for about 18 months. A total of 2,100 patients will be enrolled in the study globally.

After the 18 months of participation in the study, there will be an optional extension study in which patients who have completed the study will have the opportunity to receive open-label treatment with solanezumab.

AD is an age-related neurodegenerative disorder characterized by a progressive decline in cognitive function and ability to perform activities of daily living. The Aβ hypothesis for AD states that the production and deposition of Aβ in the brain is an early and necessary event in the development of AD. This theory suggests that treatments that slow the deposition, or buildup, of Aβ or that increase its clearance from the brain might be expected to slow the progression of AD. ■

If you would like more information about participating in the Expedition 3 clinical trial, please contact Carolyn Rickard at 412-692-2707 or mishlercj@upmc.edu or MaryAnn Oakley at 412-692-2721 or oakleym@upmc.edu.

Walk to End ALZHEIMER’S a Success

On October 5, 2013, Team ADRC united in a movement to reclaim the future for millions. We participated in the Alzheimer’s Association Walk to End Alzheimer’s, the nation’s largest event to raise awareness and funds to fight Alzheimer’s disease (AD). ADRC faculty and staff believe in the association’s mission and that we can advance research to treat and prevent AD and provide programs to improve the lives of millions of affected Americans.

This year, the Walk to End Alzheimer’s was held at a new venue: Pittsburgh’s North Shore. The walk began outside the FedEx Great Hall at Heinz Field. The weather was on our side (after a brief rain shower), and it proved to be a beautiful day for walking for a great cause.

The Walk to End Alzheimer’s united our community—family, friends, coworkers, social and religious groups, businesses, and more—in a display of combined strength and dedication in the fight against this devastating disease.

The Alzheimer’s Association’s mission is to eliminate AD through the advancement of research, to provide and enhance care and support for all affected, and to reduce the risk of dementia through the promotion of brain health. The University of Pittsburgh Alzheimer Disease Research Center will continue to partner with the Alzheimer’s Association to work toward our shared vision of a world without AD and related dementias. ■
In April, President Barack Obama announced the Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative. This is a 15-year $100 billion project aimed at developing the technical capacity to observe the activity of individual neurons and the interaction between neurons in the brain. This year, the initiative will be launched with a $100 million investment to plan its overall strategy. This is an exciting venture. Its scope dwarfs that of the Human Genome Project, which has already begun to yield benefits in the area of personalized medicine. The mission—to understand how the brain works at its most fundamental levels—is breathtaking, and it provides hope for all of us engaged in seeking the cure for Alzheimer’s disease (AD).

It is important to bring perspective to bear on the initiative. First of all, it is encouraging to see this kind of federal investment in brain science, but the answers will not come quickly. The BRAIN Initiative will eventually benefit those who suffer from disorders associated with the brain and the central nervous system, such as those with traumatic brain injuries (like wounded warriors returning from distant conflicts), Parkinson’s disease, Down syndrome, and AD. Such results may still be years away. In the meantime, the BRAIN Initiative will support the development of new and more sensitive ways to examine how the brain works. Some of the innovations may have immediate payoffs in identifying new targets for therapies or providing new and more precise methods to measure the effects of therapies.

An important measure of our national commitment to developing the map of brain activity, which is the goal of the BRAIN project, will be sustained support that does not draw resources away from ongoing research aimed at understanding and curing AD.

Ken Hepburn is an ADRC faculty member and professor in the Nell Hodgson Woodruff School of Nursing at Emory University.
Alzheimer’s disease (AD) awareness and education in the African American community continues to be a priority at the Alzheimer Outreach Center. Center staff members remain vigilant in their efforts to maintain a presence in the community and raise awareness of AD.

The most recent educational events that have taken place are as follows:

- Southwestern Pennsylvania Area Agency on Aging, Inc.’s 27th Annual Senior Games
- Mount Ararat Baptist Church’s second annual Super Senior Health Expo
- Lemington Community Services’ monthly birthday luncheon
- Arden Courts of Monroeville’s Health Expo
- Educational presentation at the Thelma Lovette YMCA
- Pennsylvania State Representative Dan Deasy’s Senior Health Expo at Guardian Angels Parish in Green Tree, Pa.

The fall 2013 Walter Allen Memorial Seminar Series was held on October 3, 2013. Lawrence A. Frolik, JD, professor of law at the University of Pittsburgh School of Law, spoke on How Proper Planning Can Avoid the Need for Guardianship. The topic of elder law was proposed by the ADRC’s Community Advisory Council. The lecture was well attended and well received.

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

Thanks and Best Wishes to Beth Sarles

After 11½ years at the Alzheimer Disease Research Center (ADRC), Beth Sarles has moved on to pursue a doctoral degree in epidemiology at the University of Pittsburgh. Sarles began working at the ADRC in 2001 as a neuropsychometrist. In the ensuing years, her responsibilities grew to include working as a research coordinator for a number of clinical trials as well as heading up the neuropsychology program. Sarles has been a wonderful asset to the ADRC and truly will be missed.

ADRC University of Virginia Satellite

At the Alzheimer Disease Research Center (ADRC) University of Virginia satellite, we have been focusing on community outreach during the summer and early fall of 2013. Our goal has been to find various opportunities to inform the African American community, specifically in the Charlottesville, Va., and surrounding rural areas, about the benefits of participating in research aimed at understanding cognitive decline within this high-risk population.

In the summer, we participated in the Charlottesville Community Health Fair, which was held in conjunction with the 24th Annual African American Cultural Arts Festival. The event covered all aspects of health, including vital screenings, mammography, vision and hearing testing, peripheral artery disease testing, a bone marrow registration drive, youth sports physicals, research study information, health education, and counseling. There were approximately 500 attendees at the event, and we were able to discuss the goals of the ADRC with a number of families. As a result, some people have decided to participate as ADRC volunteers.

In early fall, staff members participated in the successful Walk to End Alzheimer’s to support the Central and Western Virginia Alzheimer’s Association Chapter, with whom we partner on other outreach opportunities throughout the year.

The fall 2013 Walter Allen Memorial Seminar Series was held on October 3, 2013.
In Memoriam

The University of Pittsburgh Alzheimer Disease Research Center thanks the following individuals and companies for their generous donations received between April 20 and October 22, 2013.

In Memory of Helen Adams
Staff of the Health Studies Research Center, University of Pittsburgh

In Memory of Gertrude Archer
Sharon Gall

In Memory of Elizabeth Bachman
Capitol Granite Company
Joel Kennet
Nomak Development Corporation
Michael Kamon and David Steinbach
Nomak Custom Homes

In Memory of Alice Braseh
Sylvia Reznick

In Memory of Eleanor Budinsky
Kenneth, Keith, and Rose Altemare
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Charles and Jenny Elliott

In Memory of Ann Chenfery
Daniel and Georgiann Kralik

In Memory of Marion Weis Cohen
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Edward Finn
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Joan Kaplan
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Jean Simon

CORRECTION from the spring 2013 Pathways

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South Hills Gastroenterology
Linda Sudnik
Alan and Linda Verbofsky
Waterfront Surgery Center, LLC

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James and Marie Hanuscin
Order of the Eastern States, Hartford Chapter

In Memory of Clyde R. Orr
William and Jean Stanhagen
In Memory of Wayne Schuetz  
Roberta Marie Churilla

In Memory of Wayne Shoemaker  
Genelle Smith

In Memory of Norman Shor  
Janice Mandel  
Priscilla E. Sloss

In Memory of James R. Taylor Sr.  
Allegheny Valley School, Former Friends and Coworkers  
Keith and Kristy Mosur  
Toni J. Pace

In Memory of Marian Terris  
John and Shelley Hulland

In Memory of Hildegard Urban  
Helene S. Russell

In Honor of Glenna Sue Baker  
Jason and Leslie Baker  
Carpenter’s Towing Service, Inc., d.b.a. Carpenter’s Auto Repair  
The Morris and Phyllis Friedman Foundation  
Charles and Beverly Gallagher  
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New Beginnings Hair and Tanning  
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Peter and Lynn Antenucci

In Honor of Kenneth Phillip Heiss  
The Peabody Class of 1959

In Honor of John H. Manes  
Betty Manes

The DeMoes Fund—DIAN Research Study  
In Memory of Gail DeMoe  
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Betty Lou Yount Trust  
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Thank you!

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.
NEUROSOCOMETRIST CATHY STERLING

One day, while working as a computer instructor and consultant, Cathy Sterling realized that her ideal job would involve conducting research in an area in which she feels personally committed to serving.

“Three of my family members’ deaths were attributed to dementia and Alzheimer’s disease [AD]. For this reason, it is truly rewarding to me to be a part of this center, where the clinicians, doctors, and administrators have dedicated themselves to the purpose of helping patients and families deal with this disease. They are a great group of dedicated professionals to work with [and] are determined to find a solution to the AD puzzle.”

Since August of 2013, Sterling has primarily been responsible for administering paper-and-pencil cognitive tests to Alzheimer Disease Research Center (ADRC) participants. In addition, she assists with organizing weekly consensus meetings.

Prior to working in her current position at the ADRC, Sterling served as the project coordinator for the Pittsburgh Girls Study (Mother Baby Study and Teen Mom Study) at UPMC and as a research specialist at the University of Pittsburgh investigating the usefulness of memory screening in primary care and the impact on clinical and cognitive outcomes of providing cognitive reports to physicians. The study used a portable computer to assess memory and thinking. Sterling was responsible for recruiting participants, administering memory tests and conducting interviews, and testing the portable computer tablets used to assess memory and thinking abilities. In addition, she also served as the project coordinator for the ADRC Smart Brain (Brain Fitness) study.

Sterling earned a Bachelor of Science degree at Purdue University and is currently enrolled in the Graduate Certificate in Gerontology program at the University of Pittsburgh.

Sterling’s hobbies include photography, lacrosse, gardening, exercise and nutrition, and spending time with her grandchildren.

Visit Our Web Site

For up-to-date information about the Alzheimer Disease Research Center, the brain donation program, clinical trials, and community presentations, please visit www.adrc.pitt.edu.

Staff Spotlight

“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.”

-Cathy Sterling
Support Group News

We are excited to announce a new collaboration between the Alzheimer Outreach Center (AOC) and Zeta Phi Beta Sorority, Inc. The local Lambda Lambda Zeta chapter of Zeta Phi Beta, an international historically Black Greek organization founded in 1920, will be sponsoring the AOC’s monthly caregiver support group as a part of its national elder care initiative.

Zeta Phi Beta was founded on the simple belief that sorority elitism and socializing should not overshadow the real mission for progressive organizations: to address societal mores, ills, prejudices, poverty, and health concerns. Through its Z-HOPE care initiatives, programs, and projects, Zeta Phi Beta is able to provide thousands of hours of valuable service to local communities.

The first sponsored caregiver support group meeting took place on Tuesday, September 24, 2013. Elaine Dively, a retired social worker and former employee of the Alzheimer’s Association Greater Pennsylvania Chapter, was the featured guest speaker. Dively spoke on the effects that Alzheimer’s disease (AD) has on the brain and the behaviors that result from the disease.

We are appreciative of Zeta Phi Beta’s sponsorship for the next year and look forward to future collaborations.

The AOC is the community satellite and outreach program of the Alzheimer Disease Research Center and has been part of the community since 1992. The caregiver support group provides emotional, educational, and social support for family and friends of those with AD and other related dementias.

Meetings for caregivers are held on the last Tuesday of every month from 6 to 7:30 p.m. at the Alzheimer Outreach Center at the Hill House Association, 1835 Centre Avenue, Suite 230, Pittsburgh, PA 15219.

For more information, call Marita Garrett at 412-692-2722.

ADRC Expands Program with the Andy Warhol Museum

For the first time, Pitt’s Alzheimer Disease Research Center (ADRC) is expanding a program that brings adults suffering from dementia to the Andy Warhol Museum to tour the museum, take part in a studio art activity, and engage in discussions about art.

The program for ADRC participants began in 2010 with activities surrounding a visit from Brazilian artist José Rufino, whose work deals with memory and the concept of interpersonal loss. The following year, the Warhol/ADRC partnership was solidified through the creation of the A HA! (Art, Health, and Alzheimer’s disease) initiative, which seeks to explore ways in which the worlds of art and Alzheimer’s disease research can come together to promote creativity, raise public awareness of the disease, and sustain or improve well-being among persons or families affected by dementia. The central part of this partnership has been a program in which groups of patients and caregivers participate in a creative expression project involving a combination of museum and studio art activities at the Warhol.

Now, the ADRC has opened up this program to the general public, offering it to all local adults who are suffering from dementia. The next session will be on Thursday, March 20, 2014.

For more information, please contact MaryAnn Oakley at 412-692-2721 or oakleym@upmc.edu.
Volunteers Needed for Research Studies

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**
- A diagnosis of moderate to severe Alzheimer’s disease with behavior problems/agitation
- A study partner who will accompany you to all study visits

Learning New Fact Knowledge through Reinforcement

**DESCRIPTION**
This is a behavioral study that investigates 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 LENGTH**
One visit that lasts approximately two hours

**STUDY REQUIREMENTS**
- Participants with a diagnosis of Alzheimer’s disease
- ADRC control participants
Objective Evaluation of Family Caregiving 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 LENGTH
Three to four months

STUDY REQUIREMENTS
- Family caregiver age 21 or older who lives with and provides care to a person with moderate to severe dementia
- Person age 50 or older with moderate to severe dementia whose behavior is difficult for the caregiver
- Willingness to engage in all study activities at home and by phone

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

Contact
MaryAnn Oakley at 412-692-2721 or oakleym@upmc.edu

The University of Pittsburgh Alzheimer Disease Research Center (ADRC) is looking for volunteers with and without mild memory loss to participate in its research.

Please call the ADRC at 412-692-2700 for more information or to inquire about how you can volunteer for research to help fight Alzheimer’s disease, or visit our Web site at www.adrc.pitt.edu to download a memory evaluation application.
By Eric McDade, DO

Q: Can Alzheimer’s disease really be diagnosed by smelling peanut butter?

A: The sense of smell is an impressively complex system. It allows us to experience the world around us in a number of ways. Most of us are familiar with the experience of how a smell can transport us back to a previous place or time. Researchers of Alzheimer’s disease (AD) and related disorders, such as Parkinson’s disease and Lou Gehrig’s disease, have been looking at how the sense of smell might be helpful in detecting changes in the brain associated with these disorders.

Researchers from the University of Florida McKnight Brain Institute and Center for Smell and Taste recently published an interesting study looking at the usefulness of peanut butter in diagnosing AD and distinguishing it from other types of dementias. The paper, published in the Journal of the Neurological Sciences, used a very simple approach:

• Patients coming in for AD testing were asked to close their eyes and mouth and block one nostril.

• A clinician then held out one tablespoon of peanut butter at the end of a metric ruler and moved the peanut butter toward the open nostril one centimeter at a time until the patient could detect the smell.

• The distance between the ruler and nostril at the time when the patient could smell the peanut butter was recorded. The same procedure was repeated using the other nostril.

The experiment was conducted in three other groups of older adults: those without memory problems, those with mild memory problems, and those with memory problems believed to be from dementia not caused by AD.

They found that the older adults without memory problems were able to detect the smell of peanut butter equally in both nostrils. The group diagnosed with AD had much less ability to detect the peanut butter smell in the left nostril as compared to the right nostril. And among the patients with the most severe AD, it was difficult to detect the smell in either nostril. The older adults with mild memory problems had patterns similar to those with AD.

Based on this study, the researchers proposed that a simple smell test might be a useful step in confirming a diagnosis of AD, especially early on in clinics where more sophisticated testing is not available and when the symptoms are still relatively mild.

It is important to note that readers should not assume that because their sense of smell has changed they have AD. The Alzheimer Disease Research Center wanted to highlight this study because of how simple and low-tech the test was and how large the differences were between the groups. There were, however, important limitations of the study, including the fact that those diagnosed with AD were more cognitively impaired than the other groups, which could account for some of the results. In addition, researchers also found that there was a group of participants with the opposite pattern, in whom the right nostril was more affected than the left nostril.

Lastly, excluded from the study were any participants who had problems with their sense of smell for other reasons, such as due to medications, allergies, and environmental exposures. Although the results of this research are exciting, more research will require larger groups of people to be tested for the findings to be confirmed.

As most of us involved in brain research understand, the mind is beautiful yet incredibly complex, and rarely is there one simple explanation for something as complex as AD. This study does, however, support further research into disorders of smell in those who have been diagnosed with AD and other types of dementia.