

SHILEY-MARCOS ALZHEIMER'S DISEASE RESEARCH CENTER

CURRENTS

UPDATES IN RESEARCH AND RESOURCES



The Shiley-Marcos ADRC Has Moved!

On September 19th, the Shiley-Marcos Alzheimer's Disease Research Center (ADRC) moved to a new location that is strategically located at the hub of the growing UC San Diego Medical Campus. Our offices are now based in the East Campus Office Building (ECOB) near the new Jacobs Medical Center and the Clinical and Translational Research Institute. This closer proximity to our campus-based faculty and colleagues will help to enhance our partnerships with other research groups and facilitate a comprehensive approach to our care of people with Alzheimer's and related disorders in our clinics, as well as in our research endeavors at our ADRC. Our new offices will provide us with state of the art physical space to see patients and families, and we will have greater access to innovative equipment that is helpful in implementing our research efforts. The Shiley-Marcos ADRC is nationally recognized for our contributions towards the prevention, treatment, and ultimate cure of Alzheimer's and related disorders, and this move is intended to foster further growth and commitment to our ADRC as we continue to advance these efforts.

continued on page 2

Our New Program Director Emily Little



What drew you to the Shiley-Marcos ADRC?

I became aware of the Shiley-Marcos Alzheimer's Disease Research Center (ADRC) as I was searching for the best care available in San Diego for my grandfather and his centenarian wife. I had arranged my work-life to allow for flexibility to help care for them, but when I came across an opportunity to contribute to a solution for not only my grandparents, but for my generation's grandparents and parents, I became cautiously impassioned. My first discussion with Mary Sundsmo (see page 2) about how I might contribute to the Shiley-Marcos ADRC administration drew me, as if magnetically, to the research center and the hope that it represents for scientific discovery leading to a treatment and cure of Alzheimer's disease. The dedication of the faculty to generate knowledge about memory disorders was apparent to me before I had even completed my interview process. The warmth of the staff that I have witnessed towards prospective and enrolled research participants and their study partners in my first 90 days has only affirmed my decision to make a commitment to this center. The Shiley-Marcos ADRC conducts itself with the values of equity, transparency,

continued on page 3



ADRC Has Moved!

continued from page 1

Any move involves an array of adjustments during the transition. Our ADRC families remain at the forefront of our priorities during this time, as your continued participation in our groundbreaking research is critical to our progress and success. We will make every effort to make this transition as smooth as possible for you. Many people can be intimidated by the idea of navigating the UC San Diego campus, but the Shiley-Marcos ADRC shares easy free-way access with other prominent UC San Diego medical and research buildings. Please see our directions below. We have free ADRC-designated parking spaces directly in front of our new building, and our offices are on the first floor for particularly easy access.

As we move forward with our research projects and goals, we will strive to meet our families' educational and support needs by continuing to offer our array of Quality of Life programs to complement research opportunities. In order to ensure ample parking and accommodation for our support groups, we have established new sites for our weekly and monthly meetings. See box to the right.

We are deeply thankful to our dedicated participants, volunteers, multidisciplinary researchers, and community partners for your ongoing commitment and support.

Please do not hesitate to reach out to us if you face any unexpected challenges as we make this important transition together. We look forward to seeing you at our new location!

Our phone number will remain the same: (858) 822-4800

The new address is:
9444 Medical Center Drive, Suite 1-100
La Jolla, CA 92037-0948

Directions to our new offices are as follows:

FROM THE NORTH:	<ul style="list-style-type: none"> • From I-5 exit Genesee and go left • Turn right on Campus Point Drive. (You will see a big white sign that says “UCSD Health Systems”) • Continue through the stoplight and then turn right at the first stop sign onto Medical Center Dr. • Turn right at the second stop sign • Keep going past the Emergency entrance • You will approach another “UCSD Health Systems” sign on your right • Turn left after the sign into the small parking lot. Our building is adjacent to the new Jacobs Medical Center. Park in spots that say ADRC.
FROM THE SOUTH:	<ul style="list-style-type: none"> • From I-5 exit on La Jolla Village Dr. and go right • Turn left on Genesee Ave. and keep going straight • Turn left on Campus Point Drive. (You will see a big white sign that says “UCSD Health Systems”) • Continue through the stoplight and then turn right at the first stop sign onto Medical Center Dr. • Turn right at the second stop sign • Keep going past the Emergency entrance • You will approach another “UCSD Health Systems” sign on your right • Turn left after the sign into the small parking lot. Our building is adjacent to the new Jacobs Medical Center. Park in spots that say ADRC

NEW Shiley–Marcos ADRC Support Group Meeting Sites

The following support groups will continue to be facilitated by our Shiley-Marcos ADRC Clinical Social Worker, Tracey Truscott, LCSW but now meet at different locations:

The weekly Early-Stage Support Group meets at:

Congregation Beth Israel
9001 Towne Center Drive
San Diego (UTC area)
For directions, contact Tracey Truscott at (858) 822-4800

Our three monthly support groups include one for participants with Young-Onset Dementia; a Lewy Body and Frontotemporal Dementia caregiver group; and a general caregiver support group. These groups are still facilitated by Tracey Truscott, but are now held at:

Alzheimer’s San Diego
6632 Convoy Court
San Diego (Clairemont area)
For directions call: (858) 492-4400

Emily Little *continued from page 1*

balance, and excellence, so who wouldn't be drawn that?!

Tell us about your professional background. I completed my Bachelor of Arts with a major in Biochemistry and Molecular Biology at Mills College in Oakland, California and my Master of Public Health at the Johns Hopkins Bloomberg School of Public Health in Baltimore, Maryland. My career began with a Barrett Scholarship to do basic research on genes involved with learning behavior in *C. elegans* (small worms). I then experienced a shift in focus from basic to clinical and translational science. At the University of California, San Francisco (UCSF), I coordinated studies of the rate at which pharmaceuticals are absorbed and excreted by the body to determine safe and effective doses of new medicines. Alongside my appointment at UCSF, I worked with small-business research operations, start-up companies, and private medical groups to bring new medicines to market. As my interests progressed beyond basic biology and medical sciences, I continued my education in public health research and practice. During my tenure at Johns Hopkins I contributed to a wide range of research, evaluation, and program development initiatives centered around patient-centered outcomes research. I decided to step outside of academic life in late 2014 to travel and expand my horizons, spend time with family, and find a place that would allow me to bring the breadth of my training to help

build a healthier and more peaceful, sustainable future.

What do you hope to bring to your role and to the team at the Shiley-Marcos ADRC? I hope that my training and personal experience to date will help me to articulate how each effort under the Shiley-Marcos ADRC umbrella contributes to bridging scientific discovery with best clinical practice and community care for those whose lives are impacted by Alzheimer's and related disorders. I aim to be responsive to the direction of our senior leadership and to advocate for broader accessibility to our programs. My goal is to be helpful in sustaining, enriching, and expanding what the research center has to offer to the community and to preserve the success that the Shiley-Marcos ADRC has achieved over the last 33 years.

What do you do for fun? I play in my side yard that I have converted into a vegetable garden. I call it my "yarden." One day I hope to have a sustainable urban farm, complete with chickens and maybe a pig or a goat, but until then... I ride bicycles, and spend time with friends and family cooking, eating, and telling stories.

We are excited to have Emily Little on board with our team and look forward to working with her as we continue to advance our Shiley-Marcos ADRC projects and goals.



Mary Sundsmo, proud grandmother to infant, Brecken, and 2 year-old Grayson

Mary Sundsmo Retires

On July 19, over 100 people gathered at the Shiley-Marcos ADRC to honor our retiring Program Director, Mary Sundsmo, and to thank her for her years of dedication to work in Alzheimer's and related disorders both in UC San Diego labs and at the ADRC. We are deeply grateful to Mary for her warm leadership and steadfast commitment to the ADRC, and we wish her all the very best in her retirement. The following is Mary's message:

After 18 years at the Shiley-Marcos ADRC and 32 years at UCSD, I made the decision to retire. I came to the ADRC in 1998 after working on campus in an Alzheimer's research lab. At the time, I knew quite a lot about the molecular biology of Alzheimer's disease but very little about the clinical side of the disease. All the knowledge I have today has been gained from our ADRC staff, faculty and our wonderful ADRC families. Thank you all. Looking back on the highlights of my career at the ADRC, my involvement in public policy at both the state and federal levels are high on the list. In 2000, Leon Thal and I sought to change the law in California to allow for a surrogate to consent to participation in research on behalf of someone who did not have decisional capacity. We were successful and our bill became law and was a nationwide model for surrogate consent. I also served on the CA State Plan task force, publishing our State Plan in 2011. Close behind in my highlights is helping our national NIA program learn to navigate the electronic grant submission system. I made life long friends among my fellow administrators as we surmounted the challenges of complex grants together and helped keep our Shiley-Marcos ADRC funded. Retirement will be sweet for me as I spend more time with my family, especially my two grandsons. I also hope to travel, read and garden.

Valued Support Group Volunteers

by Lisa Snyder, LCSW

The Shiley-Marcos ADRC has long offered a variety of Quality of Life programs to address the social and educational needs of persons with dementia and their caregivers, including a range of support groups. Here, we honor three extraordinary volunteers who help to make two of our support groups possible.



Jayne Slade and Joyce Camiel

Early-Stage Support Group

Our center's weekly early-stage support group began in 1995 with a unique support group for persons diagnosed with Alzheimer's and a separate concurrent support group for an accompanying caregiver. Joyce and her husband, Shimon, joined the support group together in late 2003 followed in a few months by Jayne and her husband, Hank. Jayne and Joyce saw each other through the Alzheimer's journey until their spouses passed away. In the process, they remained deeply connected to the weekly caregiver group. Gradually, and very generously, they assumed roles as dearly valued co-facilitators for this peer-led meeting. Jayne reflects on the rich history that she and Joyce share and says, "The fact that Joyce and I began coming to ADRC at almost the same time has made our partnership as facilitators a lot more successful as a team because we agree on nearly everything and can elaborate on a forgotten strategy or a point being made by the other."

"Co-facilitating the group is the highlight of my week," says Joyce. "I walk away feeling like I am paying it forward, helping others to gain insight into their own journey, just as others helped me when I was an attendee. I love sharing what I've learned from my own personal experience." Jayne affirms the feeling of satisfaction from being able to help others on the journey. "Probably the most gratifying part for me," she says, "is the appreciation of the group and their weekly expressions of gratitude for the knowledge and encouragement that we have tried to impart... I really love our support group participants and admire their tenacity and determination to do the absolute best job possible."

Peer support and guidance can have a profound impact, as advice or insights are often better received when they come from someone who has walked the path. The process of peer facilitating is a skillful art, however, and both Jayne and Joyce recognize the responsibilities inherent in their role. Joyce says, "The greatest challenge is to not give advice or make suggestions too quickly and to help folks try to figure out how to resolve their issues on their own. It empowers them to feel like they are doing it themselves."

"Each person has his or her own learning curve which cannot be rushed," says Jayne. "It can be hard to find the right words to dispel assumptions and ideas that do not contribute to their loved one's well being, while continuing to encourage positive behaviors and learning that will absolutely make a huge difference on both ends. Associating with the Shiley-Marcos ADRC and the stellar people there also keeps me in the loop of the latest advances in Alzheimer's. That allows me to answer questions out in the community, which seem to come up constantly."



Ken Fousel

Lewy Body Dementia and Frontotemporal Dementia Support Group

In January, 2011, The Shiley-Marcos ADRC partnered with the San Diego Chapter of the Alzheimer's Association (now Alzheimer's San Diego), to establish the county's first support group for caregivers of persons with Lewy Body Dementia or Frontotemporal Dementia (the two most common non-Alzheimer's dementias). This group would not have happened without the steadfast advocacy and commitment of Ken Fousel, a devoted caregiver of his wife, Liz, who had

Volunteers *continued from page 4*

Alzheimer's for nearly 20 years, followed years later by his next partner, Lynne, who was eventually diagnosed with Frontotemporal dementia. Undaunted by these painful repeat challenges, Ken worked tirelessly to learn as much as possible about these dementias and to share that knowledge with others. Ken has co-facilitated our monthly non-Alzheimer's dementia caregiver support group since its inception and now works with our clinical social worker, Tracey Truscott, LCSW, to provide support to families dealing with these challenging and often overlooked forms of dementia.

"The most gratifying or rewarding outcome," Ken says, "is when one individual is struggling with a problem and is at their wit's end, and I am able to give that person the information and emotional support they need at that critical moment or stage of their life. It is always good to be able to impart useful information to the whole group, but often you never know just who is needing that information or insight right at that moment. So when I can see and feel the emotional response from a person and know that I made a significant and positive impact on their life, that is the best reward ever!"

Like Jayne and Joyce, Ken has recognized over the years that each caregiver learns at his or her own pace. He says, "It's a challenge to know when enough information is enough - not to overload someone with information that they can't absorb and assimilate. When I know so much about an issue and really want to help, I instinctively want to share what I know. To immediately sense that fine line is critical - to know when enough is enough, at least for that moment."

This respect for both the uniqueness and common themes in each caregiver's journey has made Ken a valued resource to countless families who have experienced his big heart. "One of the greatest frustrations and disappointments is when you cannot provide the information and/or emotional support needed at that precise moment," says Ken. "Often their sense of their despair is palpable - you just want to reach out and hug them!"

We are deeply grateful to Jayne, Joyce, and Ken for their extraordinary dedication and commitment to helping fellow caregivers. Their countless hours of volunteer service to our research center families and greater San Diego community are an ongoing and invaluable gift.

Cognitive Decline in Hispanic versus non-Hispanic Spousal Alzheimer Caregivers

By Guerry Peavy, PhD

Caregivers of patients with Alzheimer's disease (AD) experience significant, often prolonged stress. This can lead to poor health and difficulties with thinking (e.g., memory, problem solving) that challenge their ability to meet the demands of the caregiver role. Caregivers with a spouse with AD are often vulnerable not only to difficulties associated with caregiving, but also to the increasingly harmful effects of stress due to aging.

Differences between Hispanic and non-Hispanic caregivers in cultural and genetic characteristics may lead to differences in how they react to chronic stress. Hispanics are the largest minority in the United States, but there are very few studies addressing the negative consequences of stress on Hispanic caregivers of a spouse with AD. To address the need for additional

studies, we have obtained funding to measure changes in thinking in Hispanic and non-Hispanic caregivers that may result from chronic stress. We will also address cognitive change in a combined group of Hispanic and non-Hispanic caregivers compared to older, married non-caregivers. Finally, we will investigate how specific factors that may increase the chances of developing AD (e.g., inherited risk factor, cardiovascular illness) combine with prolonged stress to affect cognition.

All caregivers and non-caregivers will be 55 years of age or older and functioning independently in daily activities when enrolled in the study. The majority of the study participants will be recruited from caregivers of Hispanic and non-Hispanic participants at our Shiley-Marcos Alzheimer's Disease Research Center. We also will recruit

participants from the community and will attempt to meet in a setting most convenient for them. In addition to providing general information (age, education, medical history), study participants will be asked to complete questionnaires to detect their current level of stress, as well as other factors (e.g., sleep disturbance) that may affect their ability to function normally in daily activities. Testing of cognitive abilities (e.g., memory, attention) will take place at the first visit and again, at a second visit approximately 15 months later. One blood draw will be required to measure a genetic risk factor for AD. Staff will include a bilingual examiner in order to include both English and Spanish-speaking participants.

If you are interested in learning about our study and your eligibility, contact Dr. Guerry Peavy at (858) 246-1272.

Observational Longitudinal Study and Related Projects

COGNITIVE AGING LONGITUDINAL STUDY (ALSO AVAILABLE IN SPANISH)

PI: Douglas Galasko, MD
CONTACT: Tracey Truscott, LCSW
 (858) 822-4800 or ttruscott@ucsd.edu

TIME INVOLVED: minimum 5 years

DESCRIPTION: The purpose of this study is to learn how the brain changes as we age. This is an observational study with no medication, with behavioral, medical, and cognitive data collection and testing as well as a neurological exam. This is done annually from the time of enrollment to death. Information about strategies for healthy brain aging is provided as is feedback about one's annual performance on cognitive testing.

REQUIREMENTS: Age 65 and older if normal cognition or diagnosis of MCI or early dementia due to Alzheimer's, FTD, or DLB; study partner; LP and MRI required; brain autopsy required.

*We are collaborating with 4 investigators (Drs. Wierenga, Bondi, Smith and Bangen) who have funded grants to examine new approaches to brain imaging using MRI, cognitive assessment and vascular assessment.

Also, together with researchers at UC Davis (Dr. Olichney) we also will be examining a sensitive brain wave recording method (called Evoked Response Potentials) in relation to MRI and cognitive testing to aid in very early detection of brain changes that may identify the earliest changes that may occur before the classic memory changes of Alzheimer's disease can be diagnosed.

We are also interested in whether research volunteers are veterans, whether they get their healthcare through the VA or not, because several of these new research studies report this information.

We continue to obtain blood and CSF samples from as many volunteers in these studies as possible, in order to match up changes in chemicals we can measure in the blood and CSF with changes in cognition and brain structure.

Clinical Trials for Persons with Normal Cognition

A4: ANTI-AMYLOID IN ASYMPTOMATIC AD

PI: Douglas Galasko, MD
CONTACT: Tracey Truscott, LCSW
 (858) 822-4800 or ttruscott@ucsd.edu

TIME INVOLVED: 3 years

DESCRIPTION: This randomized, double-blind, placebo-controlled trial will assess solanezumab (a passive, monoclonal antibody that helps the body rid the brain of beta amyloid) on persons with no symptoms of AD. solanezumab is administered via monthly infusions.

*Participants who do NOT qualify for randomization on the basis of the amyloid scan will be invited to participate in the "observational" group cohort described as the LEARN study.

REQUIREMENTS: Age 65-85; Normal cognition; study partner; MRI and PET scans required; lumbar puncture optional.

*There are plans to expand the A5 study from Europe and Japan, funded by Jansen, into the US soon. This trial will examine an oral pill for use in prevention of people at risk for Alzheimer's who have a different degree of brain amyloid than the amount that is required to qualify for A4.

Clinical Trials for Persons with Mild Cognitive Impairment

MERCK 19: EPOCH

PI: Shauna Yuan, MD
CONTACT: Tracey Truscott, LCSW
 (858) 822-4800 or ttruscott@ucsd.edu

TIME INVOLVED: 104 weeks of treatment; 12 visits over 24 months

DESCRIPTION: BACE inhibitor designed to stop the action of an enzyme required to make beta amyloid. 2/3 get study drug; 1/3 at low dose; 1/3 at high dose. Drug administered as one tablet once a day.

REQUIREMENTS: Age 50-85; stable on memory medication for 3 months or no memory medications, 5 MRIs, 6 ocular exams, 1 PET scan, study partner.

Clinical Trials for Persons with Alzheimer's Disease

The IDEAS study is sponsored by CMS to assess whether obtaining an amyloid PET scan on someone older than 65 with memory or other cognitive changes can change the confidence level of a clinical diagnosis of Alzheimer's disease, and whether knowing the result of the scan has an impact on how the doctor manages the patient.

DISCOVER

PI: Douglas Galasko, MD
CONTACT: Christina Gigliotti, PhD
 (858) 822-4800 or cgigliotti@ucsd.edu

TIME INVOLVED: up to two months and will require at least five study clinic visits including a three-day stay at the clinical research unit. Compensation will be provided to enrolled participants.

DESCRIPTION: Posiphen is an experimental drug developed as an anti-amyloid medication that may delay Alzheimer's disease (AD) onset or slow the progression of possible AD-related brain damage due to amyloid build-up. Participants in Discover will help researchers learn if the experimental drug is both safe and tolerated. This is a randomized, double-blind, placebo-controlled study with a 50/50 chance of receiving the experimental drug.

REQUIREMENTS: Age 55-85; diagnosis of MCI or mild Alzheimer's disease; MMSE 24-30; study partner, MRI scan, lumbar puncture, willing to undergo extended stay in clinical research unit (2 nights)

EMERGE: BIOGEN (BIIB037)

PI: James Lohr, MD
CONTACT: Lorraine Cheng, MA
 (858) 775-8869 or Locheng@ucsd.edu

TIME INVOLVED: 2 years

DESCRIPTION: The purpose of this study is to evaluate the efficacy and safety of Aducanumab (BIIB037) in persons with early Alzheimer's disease. Aducanumab is

a human monoclonal antibody, and it is being evaluated to determine whether it can remove the amyloid plaques and slow the progression of symptoms in early AD.

REQUIREMENTS: Age 50-85; diagnosis of Alzheimer's disease; MMSE 24-30; study partner, PET and MRI scans, able to have monthly infusions.

TRIAD: AVANIR (AVP-786)

PI: James Lohr, MD
CONTACT: Lorraine Cheng, MA
 (858) 775-8869 or Locheng@ucsd.edu

TIME INVOLVED: 16 weeks

DESCRIPTION: The purpose of this study is to evaluate the efficacy, safety, and tolerability of deuterated [d6]-dextromethorphan hydrobromide/quinidine sulfate (d6-DM/Q or AVP-786) in persons with agitation

secondary to dementia of the Alzheimer's type. AVP-786 is a combination product of d6-DM with quinidine sulfate (Q) that interacts with multiple receptors to decrease behavioral disturbances associated with AD.

REQUIREMENTS: Age 50-90; MMSE 6-26; study partner, moderate to severe agitation/aggression.

UC CURES

PI: Shauna Yuan, MD
CONTACT: Christina Gigliotti, PhD
 (858) 822-4800 or cgigliotti@ucsd.edu

TIME INVOLVED: 52 weeks

DESCRIPTION: double blind, randomized, placebo controlled, pilot PK/PD, evaluating tau acetylation inhibitor salsalate for mild to moderate Alzheimer's Disease. Salsalate is a non-steroidal anti-inflammatory (NSAID),

which is used to treat arthritis. Salsalate is being tested here for its property to inhibit tau acetylation, thus preventing tau aggregation.

REQUIREMENTS: The age range is 50-85, with diagnosis of AD, MMSE 14-27. Subject agrees to LP, MRI, PET (amyloid and tau), cognitive testing study partner

The Outreach, Recruitment and Education Core

By Guerry Peavy, PhD

The Shiley-Marcos ADRC is one of 31 specialized Alzheimer's Disease Centers in the United States funded in part by program grants from the National Institute on Aging (NIA). Each of the centers is composed of at least five organizational units or cores. The duties of one of these, the ORE Core, include Outreach, Recruitment, and Education. The ORE Core is involved in almost every aspect of ADRC operations, and there is significant overlap among these three types of targeted activities.

Outreach requires identifying the needs of a number of diverse groups that include our participants, caregivers, individuals in the community, volunteers, and students and faculty from UC San Diego and other institutions. Planning and implementing activities designed to meet these needs follow. One example is support groups for individuals with specific types of problems (e.g., dementia onset at a young age, mild dementia). Outreach is often an important step towards the goal of recruitment.

Recruitment addresses the need to screen and enroll subjects to participate in the ADRC longitudinal study, as well as related research projects and clinical trials. We inform individuals who may be eligible for a study about the details involved and answer any questions they may have. We also try to identify reasons individuals may be reluctant to take part (e.g., fears or misunderstandings concerning study requirements, limited resources such as problems with transportation) to enable us to remove barriers, if possible. Of course, while we encourage individuals to participate, we are re-

spectful of their decisions regardless of the reasons. Our 3rd charge, Education, is an important way we reach out to others, and in some cases, aids in our efforts to recruit.

Education is important for helping our participants and the community to understand Alzheimer's disease (AD) and other dementias, including information about habits and activities that may reduce chances of getting the disease. Education targets many other groups, as well, and can take many

Lisa Snyder and Christina Gigliotti recently published a booklet in collaboration with the National Institute on Aging Alzheimer's Disease Education and Referral (ADEAR) Center that explained basic information about a common type of dementia, Lewy Body Dementia (LBD) featuring among other things, how LBD is different from AD. We are proud to report that more than 131,000 copies of this popular booklet have been distributed. Another collaboration with ADEAR, a booklet on 'biomarkers' (e.g., brain imaging, and measures from blood and cerebrospinal fluid) associated with AD and other dementias is underway.

The ORE Core at the Shiley-Marcos ADRC is currently composed of four individuals who meet monthly to address the wide range of activities needed to address the Core goals. Mem-

bers include the Core leader Guerry Peavy, PhD, a neuropsychologist and research investigator, Christina Gigliotti, PhD, the Center Manager of Clinical Operations, and Tracey Truscott, LCSW, the Center's Clinical Social Worker. Lisa Snyder, LCSW, although now retired, continues to work with the ORE Core as an author/editor of ADRC publications including *Currents* and *Perspectives* newsletters. Emily Little, our new ADRC Program Director, often attends our meetings as well, and coordinates efforts with the Administration and Clinical Cores.

The ORE Core has plans to bolster all three of its designated activities by focusing on new educational programs for all the groups we serve. We look forward to providing information and resources to our current participants and colleagues, as well as making new contacts.



From left to right: Tracey Truscott, Emily Little, Christina Gigliotti, Lisa Snyder, Guerry Peavy

forms. In face-to-face group informational sessions, as well as one on one sessions with members of the community, we give individuals time to ask questions to increase their knowledge and understanding of the disease. Professionals and students from multiple disciplines (e.g., neurology, nursing, neuropsychology) and institutions (e.g., VA hospitals, local universities) gain knowledge from planned and publicized lectures, organized research groups, and faculty mentors. These increase awareness of existing AD studies and help students and colleagues to generate research ideas, take advantage of ADRC resources, and pursue clinical research that may improve diagnosis and care.

Printed educational materials from the ORE Core have unlimited potential for outreach, recruitment, and education. We (particularly ORE Core members

Accurately Diagnosing Mild Cognitive Impairment

By Emily C. Edmonds, PhD



Emily C. Edmonds, PhD

“Mild cognitive impairment” (MCI) is considered a transitional state between normal aging and dementia. MCI involves a slight decline in memory or other thinking abilities, such as remembering names or a list of items. These changes are noticeable but may not be severe enough to disrupt daily life. A diagnosis of MCI puts one at an increased risk for eventually developing dementia due to Alzheimer’s disease or another type of dementia.

There is a standard screening method for identifying MCI that is widely used. Based on this method, an individual would be classified as having MCI if he or she meets the following criteria: (1) the individual reports experiencing memory problems, (2) he/she demonstrates impaired memory on one memory test that is given by a doctor, and (3) the doctor rates the person as being mildly impaired.

Researchers at the UC San Diego School of Medicine and the Veterans Affairs San Diego Healthcare System are conducting research to evaluate these diagnostic criteria for MCI. In a recently published study in the

Journal of Alzheimer’s Disease, the researchers showed that the current screening tools miss a large number of people with MCI. Specifically, over 7% of individuals in the group that they studied were misclassified as not having MCI based on standard screening instruments, but they actually did have MCI when more extensive testing was conducted.

“There are consequences to a missed MCI diagnosis,” said first author of the study Emily C. Edmonds, PhD, an Assistant Adjunct Professor in the Department of Psychiatry. “Individuals who are incorrectly identified as cognitively normal might not receive appropriate medical advice or treatment. This could include preventive measures such as lifestyle changes to maintain cognitive function, or a referral to other healthcare providers.”

In a related study, the researchers also showed that the current method for

research participants are misclassified when they enroll in a study, this can weaken the study’s results and make it even more difficult to find and develop effective treatments or therapies,” stated Dr. Edmonds.

The good news is that the researchers have offered suggestions for improving the criteria for MCI. Most importantly, their research suggests that the diagnosis should not be based only on brief screening instruments and one memory test. Instead, multiple neuropsychological tests, which are tests that measure memory and thinking skills, should be used. These tests can determine whether one’s performance is “normal” for his/her age, or whether performance is below expectation based on age-related changes alone.

By incorporating multiple neuropsychological tests into the diagnosis of MCI – a method that is routinely used at the Shiley-Marcos Alzheimer’s Dis-

“ The diagnosis should not be based only on brief screening instruments and one memory test. Instead, multiple neuropsychological tests, which are tests that measure memory and thinking skills, should be used. ”

identifying MCI can result in errors in the opposite direction. In these cases, individuals were classified as having MCI based on standard screening instruments, but they actually did not have it upon further testing. This type of error occurred in approximately 34% of individuals in the group that they studied. This previous study was published in the journal Alzheimer’s & Dementia.

In addition to having a negative impact on patient care, these errors in diagnosis can also impact research studies of MCI and Alzheimer’s disease. “If

ease Research Center – we can improve clinical research studies and better predict who is most at risk for developing dementia.

Co-authors of these studies include Lisa Delano-Wood, Amy J. Jak, Douglas R. Galasko and senior author Mark W. Bondi, all at UC San Diego and Veterans Affairs San Diego Healthcare System, and David P. Salmon, UC San Diego. Funding for this research came, in part, from the National Institutes of Health, with data collection and sharing support via the Alzheimer’s Disease Neuroimaging Initiative.

Staff News and Updates



Goodbye Martha Muniz

After two and a half years, **Martha C. Muñiz**, our senior bilingual psychometrist will be leaving Shiley-Marcos ADRC. During her time at the ADRC, she has participated in the Hispanic Core, Outreach, Retention, and Education Core, as well as in quality of life programs for English and Spanish speakers through the “My Life through the Lens” workshop in collaboration with the Museum of Photographic Arts. She will continue her career in the Alzheimer’s disease field as a Clinical Research Coordinator for the Harvard Aging Brain Study at Massachusetts General Hospital in Boston. She is eternally grateful to the staff, principal investigators, and mostly, thankful to the families she was privileged to work with. In the future, she hopes to continue providing participants and their families services that will provide answers during difficult times.



Hello Tim Cheng

Tim Cheng was born in Taiwan, and immigrated to the United States at age 10. He grew up in Seattle and graduated from University of Washington with a BS in Biology and a BS in Electrical Engineering. He worked for Motorola Government Electronics Division for 21 years as a design engineer, and then moved into engineering management, technical marketing, and business development. Sixteen years ago, he moved to San Diego to work for Qualcomm in sales where he was responsible for sales to China, global business development, and technical support operations. He worked for Qualcomm for 11 years and retired at the end of 2016. Tim then joined the Encore Fellowship program in June 2016. The Encore Fellowship places retired corporate professionals in temporary positions at not-for-profit organizations. This means the Shiley-Marcos ADRC can benefit from a highly experienced Fellow working 1,000 hours, either full time in 6 months or part time over 12 months, while financially supported by Qualcomm. The main reason Tim selected the ADRC for this Encore Fellowship was due to his desire to learn more about Alzheimer’s disease in the hopes of helping others to better deal with it. His interest is inspired from the experience of his father’s Alzheimer’s that impacted the whole family. Tim joins our ADRC for this fellowship year as a general consultant to our research, clinical, and administrative staff, and we will no doubt put his many skills to great use!

A Grateful Welcome to Our Student Volunteers

We have many new student volunteers from UC San Diego joining our team:

Jessica Bercow will receive her BS in Psychology in June. She volunteered over the summer and will now continue to work with Jeremy Elman, PhD on a study of a novel brain imaging method aimed at early detection of Alzheimer’s risk.

Cynthia Avalos – is an undergraduate student majoring in Biochemistry and Cellular Biology. She is bi-lingual (English and Spanish) and has been working with our research assistant Sarah Espinoza, as well as helping Beata at the front desk.

Jaimie Long started volunteering in the summer. Jaimie graduated with both BS and Master’s degrees in Biology. She has experience in research, has several publications, and is currently applying to medical school. We hope to engage Jaimie in special projects.

Lisa Hou started volunteering in September. She is currently working toward a joint BS degree in Math and Cognitive Science and is interested in helping with our research data.

Gustavo Reyes is a Physiology and Neuroscience Major with a minor in Ethnic studies. He is interested in attending our support groups and engaging with the research participants.

Lilian Marquez is a Physiology and Neuroscience Major with a minor in Business. Lily will be working with Christina Gigliotti, PhD on various Outreach and Education projects.

Kimberly Lopez will receive her BS in Human Development in June. She is bi-lingual (English and Spanish) and has been working with Beata at the front desk as a

continued on page 11

A Grateful Welcome *continued from page 10*

much-valued resource assisting in administrative tasks and answering phones.

Other volunteers from outside UC San Diego include **Makeda Thomas**, a PhD student with Walden University in Counselor Education and Supervision. Makeda will work with Tracey Truscott, LCSW with support groups and offer supportive counseling education to our Shiley-Marcos ADRC families until the end of the year. **Sally Cheung** and **Nate Kwok** are Clinical Psychology students from the Chinese University of Hong Kong who are working with our senior neuropsychologist, David Salmon, PhD.

We also have had to say goodbyes. During the summer we had several outstanding high school students volunteering with us. **Sofia Llaneta** from Del Norte High School and **Alicia Pacheco** from Vista Murrieta High School helped Beata

at the front desk. We also had high school students **Charles Wang** and **Aritra Bhattacharjee** who assisted Guerry Peavy, PhD, on a project while also creating a power point presentation on dementia for the ADRC to use in educational outreach. Many thanks to these wonderful students! We also said goodbye to **Nancy Patty** who volunteered with us for over a year and was truly dedicated to our research center and our patients and families. Nancy will begin her Master of Science in Genetic Counseling at the University of Arkansas in September. **Alexander Figueroa** was an excellent student volunteer last year and assisted Nancy Patty in the completion of the interviews for the Advanced Care Planning project, a collaboration between Dr. Douglas Galasko and his colleagues at Johns Hopkins that focused on finding out more about caregivers' knowledge, thoughts, and actions regarding health care planning of patients who have memory problems or dementia.

Understanding Alzheimer's Genes

Know your family history

From the National Institute on Aging

Understanding Alzheimer's Genes

The National Institute on Aging (NIA) publishes many resources that can be very informative for families living with Alzheimer's or a related dementia. These resources can be found under the Health and Aging tab on their website at: <https://www.nia.nih.gov/>

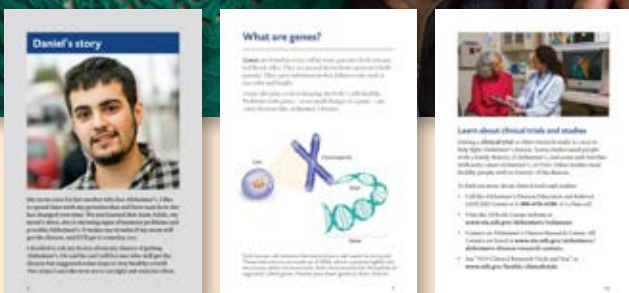
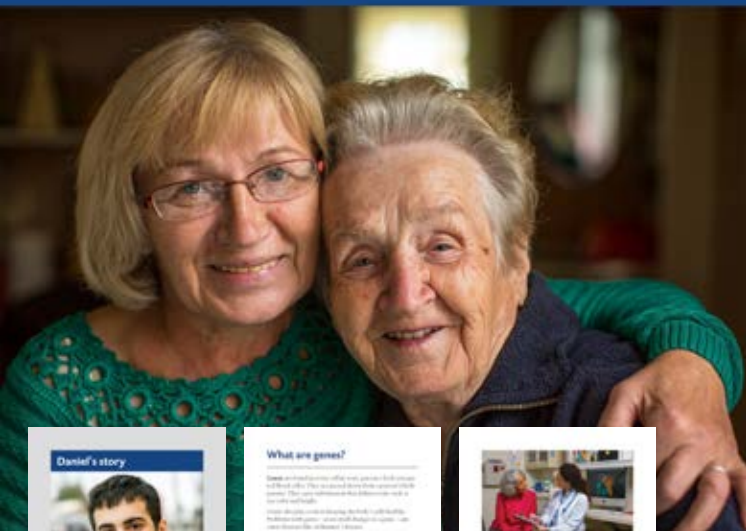
One of the newest resources from NIA is "Understanding Alzheimer's Genes: Know Your Family History." This booklet aims to help families understand the role of genetics in Alzheimer's disease. Many people wonder if Alzheimer's runs in the family. Your chance of having the disease may be higher if you have certain genes passed down from a parent. However, having a parent with Alzheimer's does not necessarily mean that you will develop it.

This booklet will help you learn:

- what genes are
- how genes relate to Alzheimer's disease
- what it means if you have a family history of Alzheimer's
- what you can do if you are at increased risk for Alzheimer's
- how to obtain more information, if needed

Read the booklet online or print it out at:

<https://www.nia.nih.gov/alzheimers/publication/understanding-alzheimers-genes/introduction>



CURRENTS

UPDATES IN RESEARCH AND RESOURCES

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2017 SERIES

Memories at the Museums



SAN DIEGO MUSEUM OF ART

January 13, May 12,
September 8

MINGEI INTERNATIONAL MUSEUM

February 10, June 9,
October 13

TIMKEN MUSEUM OF ART

March 10, July 14,
November 10

MUSEUM OF PHOTOGRAPHIC ARTS

April 14, August 11,
December 8

Join us on the second Friday of each month from 2:00 - 3:00 at one of these exceptional San Diego museums for a unique docent-led discussion and tour. Museum docents engage people with mild-to-moderate Alzheimer's or a related disorder and an accompanying family member or friend in discussions about the artwork to stimulate visual and verbal abilities and to spark memory. Memories at the Museums alternates between the four co-sponsoring museums that are all located in central Balboa Park. Museum admission and tours are *free of charge* to participants.

Each monthly tour is limited to 8 pairs (16 participants total). Pre-registration is requested. Please call Tracey Truscott, LCSW at the Shiley-Marcos Alzheimer's Disease Research Center at (858) 822-4800 to register for a tour.