

SHILEY-MARCOS ALZHEIMER'S DISEASE RESEARCH CENTER

CURRENTS

UPDATES IN RESEARCH AND RESOURCES



Young Onset Alzheimer's Disease and Related Dementias (YoADRD) Program at UCSD SMADRC

By Douglas Galasko, MD and Ivonne Arias, MSW

Onset of cognitive impairment before age 65 is uncommon, but it can have a huge impact on patients and their families. Most people with young onset Alzheimer's disease and related disorders (YoADRD) develop symptoms in their 40s and 50s. The causes of YoADRD are variable and not well understood. An accurate diagnosis of YoADRD is crucial to rule out other potential problems and get the most appropriate treatment. Issues impacting early and accurate diagnosis of YoADRD patients include:

- An initial accurate diagnosis is often delayed. Clinicians may not be familiar with young onset dementia and may not have expertise and resources for an appropriate diagnostic workup.

continued on page 2



Captain Leslie High and his wife Carol

Captain Leslie High: A Lifetime of Service

By Angie Egger, MSW

Captain Leslie High has been driven to help people his entire life. He spent 29 years in the United States Coast Guard as an aviator and a supervisor of all training commands in the Coast Guard. Since his retirement, he continues to follow this passion, helping others, through his participation in research as a healthy control subject in more than 200 studies over the past 33 years. Captain High started his journey with the Shiley-Marcos Alzheimer's Disease Research Center (SMADRC) in 1984, the year the center was first established. He has dedicated a tremendous amount of time helping SMADRC further research in the area of Alzheimer's disease and continues to participate to this day.

Captain High describes his life as "amazing", stating that, "with all I have accomplished and

continued on page 4

YoADRD Program

continued from page 1

- In patients with YoADRD, conditions other than Alzheimer's disease need to be considered, including Fronto-temporal Lobar degeneration (FTLD), immune-mediated cognitive disorders, traumatic brain injury, and unusual vascular disorders.
- Initial symptoms may not be limited to the typical memory loss characteristic of late-onset Alzheimer's disease. For example, some people start with problems affecting language, visual perception or reading, or changes in personality.
- Patients, often employed at the time of symptom onset, may be unable to continue to work. This can be highly disruptive, and families can benefit from advice about navigating social services and identifying sources of care and support.
- In some patients, genetic factors may contribute to YoADRD, leaving patients and family members to determine whether to seek genetic testing. Discussing results with patients and their families requires special expertise and in some cases may involve genetic counseling.

In order to address these gaps and expand services and research addressing YoADRD to the San Diego region and beyond, The D.H. Chen Foundation awarded funding to Dr. Douglas Galasko and colleagues to establish a YoADRD program that provides clinical assessment, social work and research opportunities for persons with YoADRD and their families. This multidisciplinary program is designed to respond to the unique challenges faced by families coping with YoADRD by providing individualized resources and referrals in English and Spanish. Specific goals of the program involve helping individuals and their families better understand their disease and its potential implications for their lives and actively assisting them in accessing and navigating services to help with coping and planning for financial and emotional well-being. Another important goal of the program is to advance science to better understand the causes, underlying mechanisms, and best treatments to minimize the devastating impact YoADRD on future generations. With the funding provided by the Chen Foundation, a group of investigators at the University of California, San Diego (UCSD), with expertise in clinical assessment, biomarkers, genetics, cell and systems biology, iPScell methods (stem cells) and drug discovery at UCSD is poised to achieve these goals.

Douglas Galasko, MD and his colleagues at UCSD, have years of experience evaluating patients with YoADRD

at the UCSD Memory Disorders Clinic. Their expertise in conducting studies as a complement to clinical care is an important foundation for understanding this unique population of affected individuals. Obtaining an accurate diagnosis sometimes requires specialized tests, that may include obtaining cerebrospinal fluid (CSF) biomarkers and brain imaging. DNA testing may involve sequencing the patient's DNA to look for alterations (mutations) in the genes. Typically, this type of detailed diagnostic testing is not covered by insurance. This research program offers opportunities for us to leverage resources to simultaneously fill the gap in coverage presented by insurance limitations, while answering questions and expanding knowledge in YoADRD.

Ivonne Arias, MSW, a bilingual social worker, works with UCSD YoADRD Program participants and their loved ones to help them understand their diagnosis, steps involved in maximizing resources available to them, and options available for research participation. The hybrid nature of this project to bridge the clinical and research realms allows the team flexibility for tailoring each person's participation to their specific needs. To illustrate the impact of the YoADRD program, we interviewed the spousal caregiver of a YoADRD participant. She agreed to share some of their experiences to illustrate the program's potential impact.

Participants in the YoADRD Program will be provided with access at no cost to multidisciplinary professionals with expertise in YoADRD for the purpose of supplementing their clinical care. They will be guided to resources and services available in the community that can promote enhanced quality of life. The program has a research focus but serves a clinical goal of consistently providing excellence in diagnostic evaluation. Patients who are assessed through the UCSD YoADRD Program will have a detailed review of any prior diagnostic evaluation. Additional testing may be recommended or ordered in some situations. Those referred to this program can contribute to research by providing clinical and biomarker data, and also will have the option of enrolling in additional research studies through the SMADRC.

Empowering persons with YoADRD and their loved ones to enhance their understanding, access, and opportunities is the goal of this program. Connecting with the specialized staff at the UCSD SMADRC can lead to a more efficient diagnosis and expanded treatment considerations. In addition, the connections to resources helps to mitigate the negative impact on family members and the potential sense of isolation common in those diagnosed

with YoADRD. We need your help to make progress in YoADRD research to advance science in this area and help future generations. If you or someone you know has been diag-

nosed with YoADRD, you can make a difference by recommending or taking part in this unique research opportunity. Research participation benefits diagnosed individuals, their families,

and future generations. **For additional information please contact Ivonne Arias, MSW at (858) 822-4800 or (858) 249-0585 or send her an e-mail at imarias@ucsd.edu.**

YoADRD Interview Excerpt

The following are excerpts from an interview with Mrs. Tapia (to honor confidentiality, Mrs. Tapia is a pseudonym) and Ivonne Arias. Mrs. Tapia was asked about her husband's journey to the diagnosis of Alzheimer's disease and her experience with the UCSD YoADRD Program. The interview was conducted in Spanish and translated for this article.

The conversation with Mrs. Tapia reveals the impact of busy lives, work schedules and lack of resources as an individual struggles to obtain a diagnosis so treatment may be prescribed in a timely manner to mitigate symptoms of the YoADRD. Mrs. Tapia highlighted this lengthy process and the value of the YoADRD team in expediting the timeline, "My journey to get (to the UCSD YoADRD Program) and this diagnosis took two years and six months. After going to UCSD, it took about two months to get the results from the MRI and... get the diagnosis of Alzheimer's disease." Some diagnostic tests that can help clarify a diagnosis are expensive for patients and their families, particularly if they are adjusting to the implications of the patient having developed incapacitating cognitive problems. Mrs. Tapia highlighted how this was true in their case and how participation in the YoADRD program provided access to an assessment that may have otherwise not been available to them, "Due to my share of cost for medical care, getting an MRI was a financial barrier for me, and UCSD provided me with different options including participation in research."

Many individuals have never considered participating in research and have reservations. Mrs. Tapia outlined her initial hesitation about the idea of being involved in

research and how participation in the YoADRD program altered that perspective when she stated, "At first, I was nervous about participating because it involves research (the skin biopsy and blood draw). Then I met with the social worker and felt more at ease during the (intake) interview. My husband was part of the interview and it felt good looking at it from his point of view and seeing that he was able to understand what was going on and able to answer questions on his own. I was so grateful for the huge help from the UCSD team of neurologists ... The program involved my husband giving a little skin biopsy and some blood to help scientists become better able to learn more about this disease and why it happens at a younger age.... I felt satisfied being able to collaborate ... in order to help others with this disease. This is doing good for everyone."

Mrs. Tapia noted that agreeing to participate in the YoADRD program benefited both her and her husband directly, while simultaneously empowering them to feel like they could make a contribution to others going through similar circumstances by sharing, "After the research portion..., we were given a folder with different resources including quality of life programs, support groups, respite care, activities, information on Alzheimer's disease medications, legal and financial planning, and understanding the disease, among other resources, such as having access to a social worker when needed. Participating in research helped us get a diagnosis and have a name to what was happening with my husband. We also contributed to something greater than this disease, a small wound that represents our participation in scientific advancement against Alzheimer's disease."



**YOUNG ONSET
SUPPORT GROUP**

**4th Wednesday of every month
12:30 pm-1:30 pm at the SMADRC**

Call (858) 822-4800 or visit adrc.ucsd.edu for more information.

Captain Leslie High

continued from page 1

all the incredible experiences I've had, I could not have asked for a better life." He was married to the love of his life for 66 years and 66 days and describes her as his one and only true love. In his words, "she was the perfect mate." Captain High was a trailblazer, not just in Alzheimer's research but in all areas of his life. His father pushed him to always be the best he could be, and he has followed this advice over the course of his entire life; being mediocre was not in his repertoire.

After the bombing of Pearl Harbor in WWII, he joined the ROTC program while at Iowa State College studying Civil Engineering. Two years later, Captain High received a Coast Guard Academy appointment where he obtained a Bachelor's Degree in Marine Engineering. He continued to strive for success and went on to receive a Master's Degree in International and Public Affairs from George Washington University and a Juris Doctor (Law) Degree from University of San Diego. Captain High dedicated 29 years to the Coast Guard focusing on improving the safety and standard operating procedures for Coast Guard Aviation. This devotion earned him numerous awards including the coveted Legion of Merit Award and he was deemed "Mr. Coast Guard." In October of 2016, he was inducted into the Coast Guard Aviation Hall of Honor.

In 2005, Captain High's wife, Carol, was diagnosed with

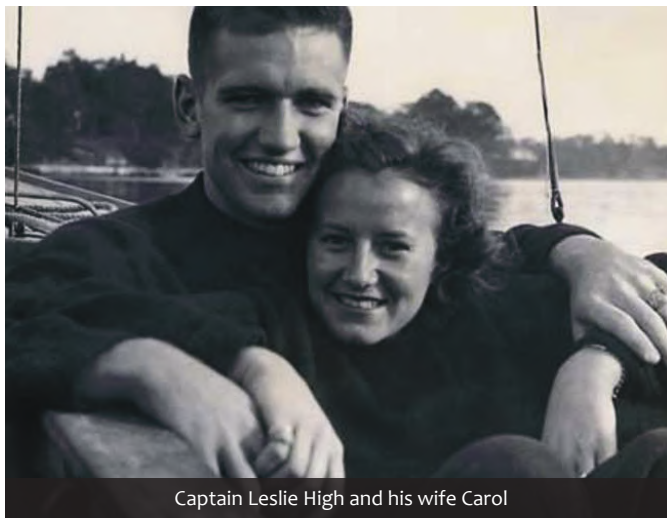
Alzheimer's disease. While most people would have been overwhelmed by the diagnosis, Captain High's experience with the SMADRC prepared him for their new journey. Because of his involvement in the center, he understood the progression of the disease and the changes his wife

was going to experience. Captain High saw his role as Carol's caregiver as a gift from God, "Carol had taken care of me for over sixty years; it was my turn to take the same great care of her." He was able to care for her at home for all but 11 days of her illness. When she was no longer able to walk for daily exercise, he pushed her in the wheelchair so she could still enjoy the fresh air. Captain High continues to walk at least 5 miles a day and last year clocked more than four million steps.

Despite his extensive accomplishments, Captain High states, "marrying Carol was the greatest." His perspective about life is refreshing and shows us that what we get out of life is what we choose to put into it. Despite Carol's passing in 2012, he continues to live life to its fullest, enjoying every minute. As he described Carol as being the perfect mate for him, he said, "she's not gone; she is still with me every hour of my life." Captain High remains thankful every day for the blessings he was given and says, "I'm the happiest 94-year-old man you will ever meet." His zest for life continues to inspire those around him and reminds us to always live life to its fullest.



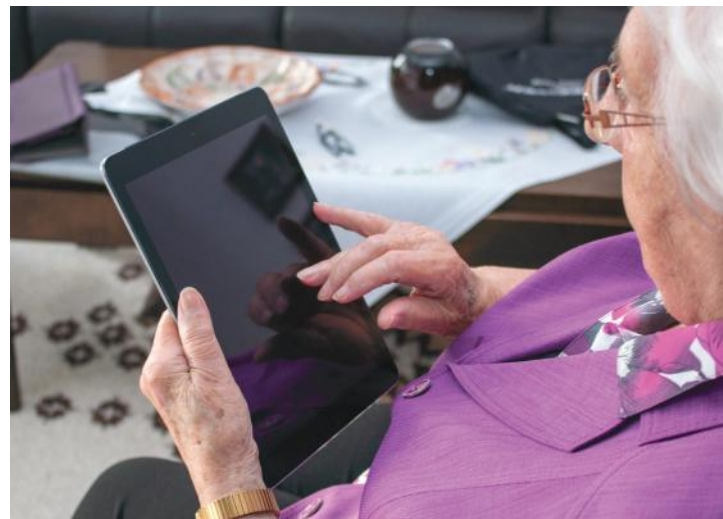
Capt. High inducted into the Coast Guard Aviation Hall of Honor 2016



Captain Leslie High and his wife Carol

Pay it Forward

Participating in research is a wonderful way to pay it forward. Research participants are the only way that scientists will successfully make breakthroughs that save lives and end devastating diseases like Alzheimer's disease and related dementias. Please consider serving others by donating your time to this noble cause. A wide array of opportunities are available for all types of volunteers! **Call (858) 822-4800 for more information.**



Introducing the ARMADA Study

By Brandon Pulido, BA

The Advancing Reliable Measurement in Alzheimer's Disease and Cognitive Aging Study, also known as ARMADA, aims to find out more about a new set of computer based tests designed to detect early signs of cognitive decline. Sponsored by the National Institute on Aging (NIA) and conducted by David P. Salmon, PhD, and his colleagues, this study is meant to overcome the limitations set in place by current cognitive screening tests which tend to be quick and convenient, but risk the possibility of failing to detect very early changes in thinking abilities. Available to English and Spanish speaking participants enrolled in the ADRC's Longitudinal Study, the ARMADA Study consists of a yearly visit to our center to complete approximately 2 hours of testing on an iPad. Participants are asked to return after one year to complete the testing again, and once again a year after that, totaling 3 visits over a span of about 3 years. Participants may also be randomly chosen to return approximately 7 to 21 days after the first visit to repeat the iPad testing in order to help us understand how performance on the tests may vary over a short time interval.

The testing is conducted using an iPad Tablet, and is designed to measure a participant's thinking abilities (e.g. memory, attention), emotional state (e.g. mood), motor functions (e.g. balance, walking speed), and sensory functions (e.g. vision, hearing, smell). As compensation for being a part of this study, participants will receive \$100 per visit totaling \$300 by the end of the 3 yearly visits, or \$400 if the participant is also one of those randomly chosen to repeat the testing over a short interval.

For more information contact Brandon Pulido at (858) 249-0572, or by email at b1pulido@ucsd.edu.

Announcing the T2 Study for Mild to Moderate Alzheimer's Disease

Alzheimer's disease, the most common cause of dementia, affects nearly 6 million Americans today. This number is expected to reach 14 million by 2050. While significant resources are being invested in finding a cure, much of the effort has focused on very early disease. Currently available treatment includes only four medications that offer only a modest, temporary improvement in symptoms.

In neurodegenerative diseases as a whole, Riluzole is the only FDA approved medication to have demonstrated any impact on illness progression. Riluzole acts by modulating the negative effects of excess glutamate, an excitatory neurotransmitter whose concentrations are elevated in most neurodegenerative disease, including Alzheimer's. Its effects are modest, in part due to difficulties in getting adequate quantities of the medication into the brain.

Enter Troriluzole. Troriluzole is a "prodrug" of Riluzole. Through a simple chemical modification Troriluzole takes advantage of the normal intestinal absorption mechanism, allowing more of the medication to enter the blood, stay in the blood, and enter the brain. Because it is absorbed so well, the medication is also much easier to take.



UC San Diego has begun a new phase 2 study, called T2 Protect AD, evaluating Troriluzole in people with mild-to-moderate Alzheimer's disease. Troriluzole may have the potential to protect against, slow decline, and eventually improve memory and thinking problems.

Clinicians at the ADRC are now seeking eligible candidates for the T2 Protect AD study. To participate in T2 Protect AD, candidates must be between 50 and 85 years of age, diagnosed with mild to moderate Alzheimer's disease, and taking donepezil, rivastigmine, or galantamine for at least three months prior to enrollment. In addition, participants must have a study partner who has regular contact with the clinical trial candidate and is able to attend study visits.

The study is sponsored by New Haven, CT-based Biohaven Pharmaceutical Holding Company Ltd., and is coordinated by the Alzheimer's Disease Cooperative Study (ADCS).

For more information, contact Nana Kori at (858) 246-3279 or by email at nkori@ucsd.edu.

Observational Studies

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: annual visit until the end of life

DESCRIPTION: The purpose of this study is to learn how the brain changes as we age. This is an observational study that collects behavioral, medical, and cognitive data and assesses neurological functioning, but does not involve a medication. 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. We continue to obtain blood and CSF samples to compare changes detected in blood and CSF to changes in cognition and brain structure.

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.

ALZHEIMER’S DISEASE NEUROIMAGING INITIATIVE 3 (ADNI)

PI: James Brewer, MD, PhD
CONTACT: Mollie Paster (858) 822-4800 or mrpaster@ucsd.edu

TIME INVOLVED: minimum 5 years

DESCRIPTION: The primary goal is to discover, optimize, standardize, and validate clinical trial measures and biomarkers used in ongoing Alzheimer’s disease research. The Alzheimer’s Disease Neuroimaging Initiative (ADNI) plays a central role in improving treatment trials. Since the study’s launch, ADNI Investigators with regulators in both the US and abroad have facilitated the design of major completed and ongoing drug trials. ADNI 3 is a

continuation of this work. ADNI 3 is a non-randomized, natural history, non-treatment study. Clinical/cognitive, imaging (MRI and PET scans), biomarker, and genetic characteristics will be assessed across the three cohorts: Normal controls (NC), Mild Cognitive Impairment (MCI), and mild Alzheimer’s disease (AD). Visits will occur annually for MCI and AD subjects and every two years for NC subjects.

REQUIREMENTS: Age 55-90; have normal cognition or a diagnosis of MCI, or AD; have a study partner; have overall good general health. Subjects are required to undergo MRI and PET scans and undergo a lumbar puncture.

EVOKED RESPONSE POTENTIALS

PI: James Brewer, MD, PhD
CONTACT: Mollie Paster (858) 822-4800 or mrpaster@ucsd.edu

TIME INVOLVED: : minimum 2 years

DESCRIPTION: This study is to examine the utility of non-invasive measures of the brain’s electrical activity as an early marker of Alzheimer’s disease. Electroencephalogram recordings (EEG) and Event-Related Potentials (ERP) have shown promise in small studies, but no study has examined how they compare to other markers more commonly used in clinical trials of Alzheimer’s disease. We will collect EEG and ERP data along with brain imaging using magnetic resonance imaging (MRI) to assess brain atrophy and use positron emission tomography

(PET) to assess for the presence of proteins associated with Alzheimer’s disease. We will determine whether EEG and ERP measures are powerful enough to serve as surrogates for these more expensive markers of disease. Clinical/cognitive, imaging (MRI and PET scans), biomarker, and genetic characteristics will be assessed across the three cohorts: Normal controls (NC), Mild Cognitive Impairment (MCI), and mild Alzheimer’s disease (AD). Visits will occur once every three years for all subjects with telephone contacts in between visits.

REQUIREMENTS: Age 60-90; fluent English speakers (as of age 12), with normal cognition or a diagnosis of MCI, or AD; have corrected visual acuity of at least 20/50 for distant vision; have overall good general health. Subjects are required to undergo an MRI, PET scan, and EEG.

Intervention Trials for MCI and Early Alzheimer’s Disease

DISCOVER

PI: Douglas Galasko, MD
CONTACT: Sandra Jerkins (858) 246-0679 or sjerkins@ucsd.edu

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

DESCRIPTION: Posiphen is an experimental drug with a novel action against amyloid and potentially other brain proteins that build up pathologically in the brain in

Alzheimer’s. It may delay Alzheimer’s disease (AD) onset or slow the progression of possible AD-related brain damage due to amyloid buildup. 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 75/25 chance of receiving the experimental drug.

REQUIREMENTS: Age 55-85; diagnosis of MCI or mild Alzheimer’s disease; MMSE 17-30; study partner, MRI scan, lumbar puncture, willing to undergo extended stay in clinical research unit (2 nights).

UC CURES SAL-AD

PI: Stephanie Lessig, MD
CONTACT: Barbara Johnson (858) 246-1303 or b4johnson@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. Sal-

salate 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, which may play a role in tau aggregation.

REQUIREMENTS: Age 50-85 with diagnosis of AD; MMSE 14-30. Subject agrees to LP, MRI, PET (amyloid and tau), cognitive testing and must have a study partner.

AWARE STUDY, ABBVIE

PI: Gabriel Leger, MD
CONTACT: Lorraine Cheng (858) 229-2283 or locheng@ucsd.edu

TIME INVOLVED: 92 weeks of treatment; 33 visits over 24 months

DESCRIPTION: The purpose of the study is to test a new drug (ABBV-8E12) which is being developed by AbbVie Pharmaceuticals. ABBV-8E12 is a humanized IgG4 monoclonal antibody against human microtubule associated protein tau. It targets soluble extracellular tau in the

brain, which has been implicated in the development and spreading of tau pathology. ABBV-8E12 may be able to block soluble tau aggregates, or seeds, from propagating between cells and thereby decrease the spreading of tau pathology and slow down Alzheimer’s disease. Drug is administered via an infusion once a month.

REQUIREMENTS: Age 55-85; stable on memory medication for 3 months or no memory medications MMSE 22-30; 8 MRIs, 3 optional lumbar punctures, 1 PET scan; study partner is required.

T2 PROTECT AD (BIOHAVEN)

PI: Gabriel Leger, MD
CONTACT: Nana Kori (858)246-3279 or nkori@ucsd.edu

TIME INVOLVED: 58 weeks total (up to 42 days of screening period, 48 weeks treatment, and 4-week post-treatment observation period, 10 total visits)

DESCRIPTION: A phase 2, randomized, double-blind, placebo-controlled trial to evaluate the efficacy and safety of BHV-4157 in patients with mild to moderate

Alzheimer’s disease. BHV-4157 is an optimized prodrug of the glutamatergic agent, riluzole, which is currently used to treat ALS. Preclinical model suggests that BHV-4157 has neuroprotective effects from AD-related pathology and cognitive dysfunction. The medication is an oral tablet taken once daily.

REQUIREMENTS: Age 50-85; diagnosis of Alzheimer’s disease; MMSE 14-24; study partner to accompany all clinic visits; cognitive testing; blood and urine sample collection; MRI; optional lumbar puncture

Lisa Snyder's Legacy

Elizabeth 'Lisa' Snyder, March 14, 1960 - February 11, 2018

The worldwide Alzheimer's community lost an innovative, creative, and deeply caring leader in the field of dementia care on February 11, 2018, due to complications from her prolonged battle with breast cancer. While we continue to mourn her loss deeply, we will remain committed to honoring her incredible life and the contributions she made to individuals, families, the academic community, and the professionals providing care and services to persons with dementia and their family members.

Elizabeth 'Lisa' Snyder was born and raised in California and received her undergraduate degree in Fine Art from Humboldt University in Northern California and a Master's degree in social work, with an emphasis in medical Social Work, at San Diego State University. During her graduate work, she completed an internship at the UCSD ADRC and immediately felt an affinity for the work. This was due partly to her own personal experiences living with her grandmother who was exhibiting undiagnosed Alzheimer's symptoms. In 1987, after graduating with her Master's degree in Social Work, she was hired at the UCSD ADRC and remained at the center as the social worker and Director of Quality of Life (QoL) programs until she retired in 2014.



During her decades of tenure at the SMADRC, Lisa achieved an incredible balance in her roles counseling persons with Alzheimer's and their families and conducting and disseminating meaningful research designed to gain insight into the often private world of persons with Alzheimer's. Lisa developed a wide array of innovative QoL programs for persons with Alzheimer's and related disorders, including one of the earliest support groups in the country for persons living with the disease. She was deeply committed to the individuals and families with whom she worked directly and also extensively engaged in providing training to professionals across the country and internationally to provide persons in the early stages of memory loss with groups of their own. She was actively engaged in collaborating with others to research the benefits of group experiences for those diagnosed with Alzheimer's. Her research and academic contributions focused on promoting greater empathy for the experiences of persons with Alzheimer's to ultimately shape and advocate for more effective care. Lisa worked

extensively toward building national and international networks with colleagues interested in all aspects of early-stage dementia. Locally, she forged a relationship between SMADRC and four museums in Balboa Park to create the Memories at the Museum Program. This program provides museum docents with specialized training on Alzheimer's and related dementias and then the museum provides them with the opportunity to utilize the training to give free monthly tours to this population for the purpose of supporting multidimensional aspects of quality of life.

Lisa did a great deal of writing, public speaking, and education about themes that arose in testimonies from

persons with Alzheimer's. Through those experiences, she found that there was great interest in hearing the 'voice' of diagnosed persons among families and professionals. She authored the books "Speaking Our Minds - What It's Like to Have Alzheimer's" (revised edition, 2009) and "Living Your Best with Early-Stage Alzheimer's - An Essential Guide" (2010). These books highlight the coping strategies used by persons with early stage memory loss to face challenges in their lives, the changes they experienced as their symptoms advanced, their relationship changes with family and friends, and their hope, humor, and resilience. Her books also highlight the ways in which we can identify

with and listen to persons with Alzheimer's to reduce the confusion and isolation that can accompany the disease. Lisa wrote and edited 89 issues of the international quarterly "Perspectives - A Newsletter for Individuals with Alzheimer's or a Related Disorder." The Perspectives newsletter was widely distributed and had an e-mail distribution list of nearly 1500 subscribers. While new issues will not continue to be generated, back issues of the newsletter are on the SMADRC website. Lisa also authored numerous peer-reviewed journal articles to inform the professional community and booklets in collaboration with the National Institute on Aging Alzheimer's Disease Education and Referral Center (ADEAR) to provide easy to understand information for persons with memory loss and their families.

Throughout her career at the SMADRC, Lisa remained inspired and enthusiastic. She was a guiding force, thought

continued on page 10

Sharing Lived Experience Through Musical Reflection: The Musical Biographies Program

By Kelley Neufeld, MSW and Dominique Hale MA, MSW Candidate



with mild to moderate cognitive decline. Formation of the program is based on techniques drawn from reminiscence and music therapies, with program outcomes focused on increasing meaningful engagement, enhancing socialization, optimizing positive interactions to reduce isolation, and promoting positive affect. Fiona Chatwin, Executive and Artistic Director of Villa Musica, a local non-profit music center which affords opportunities for musical education to people of all ages, designed the program in partnership with the UCSD SMADRC to provide an enriched biopsychosocial environment for a shared life-review activity with loved ones and supportive staff.

Each session is comprised of a weekly meeting at Villa Musica for six consecutive weeks. Participants and care partners work collaboratively with program staff to create individualized memory books and corresponding personalized playlists which reflect significant moments from their lives. Fiona Chatwin, with the help of Music Therapist, Adessa Campbell, and Book Artist, Yvonne

The Musical Biographies (MB) Program, a collaboration with Villa Musica, just completed its first official session in November 2018. First offered as a pilot program to individuals with memory loss and their care partners, the MB program was developed as an innovative Quality of Life (QoL) program to benefit individuals

Perez-Collins, guide the participants through a process to create memory books, which aligned memories from their unique social histories with associated music and artistic expression. Fiona Chatwin assists the participants with identifying meaningful songs through memory prompts and guided interviews, and even assists them in recording their own versions of the songs if the desired version isn't available. Care partners help participants personalize the pages by eliciting detailed quotes or memories associated with identified music and the personalized pages with other detailed quotes or memories associated with

identified music. Many have articulated their amazement at the ability of their loved ones to tell stories they had never before heard or describe events from the past with positive emotion and pride. In the session just completed, ADRC social work interns, Dominique Hale and Ian Beltran, coordinated the program and were present each week to provide personalized attention. The ratio of staff and care partners, available to support participants with memory loss, was 2:1. This high staff/volunteer to participant ratio optimized the participants' ability to work at their own pace and devote their energy to the component of the project they found most meaningful. It also provided an increased sense of community;

the participants demonstrated their comfort with the group by sharing their songs and experiences aloud and by working collaboratively with each other. Having had the opportunity to be creative in such a supportive environ-

continued on page 10



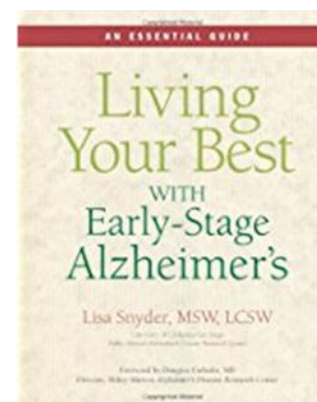
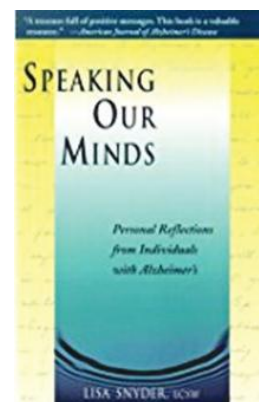
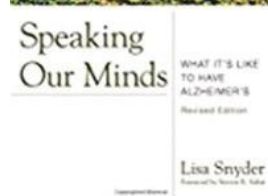


Lisa Snyder

continued from page 8

leader, and innovative program developer in the greater dementia care community. She worked for decades supporting, giving voice to, and advocating for those with memory loss and their families. We will remember her as a deeply caring person who generously shared her many gifts. She was a committed professional whose career focused on promoting personhood for individuals with dementia.

As stated by Dr. David Salmon at the annual Open House Event, “The SMADRC has plenty of brains, but Lisa has always been the heart of the center.” In her personal life, she was a dedicated philanthropist, supporting a wide range of causes that she felt passionate about locally and abroad. She was a talented artist as well as a patron of the arts. She was an adventurer who traveled extensively over the course of her lifetime, and an environmentalist who had a passion for hiking, gardening, and spending time in nature, especially in the Anza Borrego desert. Lisa lived her life with passion, empathy, and a deep concern for justice. She lived her life consistent with Gandhi’s message that we should all “be the change you wish to see in the world.” Her legacy will live on and SMADRC is dedicated to ensuring her contributions to establishing the QoL programs will continue to be a high priority for the center. We will continue to offer and expand these programs to support and give voice to persons with a wide array of diagnoses and their families.



Musical Biographies

continued from page 9

ment, each participant left the program with a fully created memory book and recorded music playlist that corresponded to the book.

At the conclusion of the program, survey responses were elicited from participants, care partners and staff. Participants indicated the MB program contributed highly to musical enjoyment as well as opportunities to interact and socialize with others and supported the development of an intimate and caring community. Most of the participants expressed interest in participating in future QoL activities. The proposed value of reminiscence combined with music that guided the development of the program was highlighted by one participant dyad’s comment that the program, “reminded us of far memories, our treasured family and friends and the impact music has had on our lives.” On the final day of the most recent session, one of the participants remarked—with a big smile on her face and tightly hugging her recently completed book—“I didn’t know I had this in me!” Hearing the participants articulate their enhanced esteem as a function of the accomplishments they gained in the program, inspires us to offer the program as an ongoing series.

The importance of QoL programs cannot be overstated, as they provide biopsychosocial benefits at the individual level, the dyad level, and the group level. The MB program will be offered twice each year at no cost to persons with memory or thinking problems and a care partner.

If you or someone you know is interested in participating, please contact Tracey Truscott, LCSW, at (858) 822-4800 or ttruscott@ucsd.edu for program dates and registration information. If you are interested in volunteering to help facilitate the program, please also contact Tracey Truscott, LCSW.



No act of kindness, no matter how small, is ever wasted.

—Aesop

Many of you have been affected by Alzheimer’s disease (AD) and related dementias. You understand the physical, emotional and financial toll these diseases can have on those diagnosed individuals and their loved ones.

Each day at the Shiley-Marcos Alzheimer’s Disease Research Center (SMADRC), we are combating the disease in the way that we know best—through forward-thinking and collaborative research. Research is the only answer to understanding this disease and discovering a breakthrough that could change the landscape of prevention, treatment and a cure for Alzheimer’s. In addition, we remain committed to providing ongoing support to individuals living with the disease and their loved ones to support dignity and enhance quality of life.

Your gift today supports:

- Young investigators conducting early-stage experiments that grow into large scale studies
- Gaps left by publicly funded research grants
- Advances in clinical interventions
- Programs designed to enhance quality of life for persons with a diagnosis and their care partners.

Each year, philanthropy allows the ADRC to support young investigators conducting novel research. Some of our young investigators include:

Dr. Katherine J. Bangen - a clinical neuropsychologist with expertise in neuroimaging of vascular injury in MCI.

Dr. Bradley Voytek - a neuroscientist with expertise in understanding the role that neural oscillations play in coordinating information transfer between brain regions.

Dr. Antonio Currais - a neurobiologist with expertise in understanding the mechanisms that link detrimental metabolic alterations in aging with the development of AD as well as drug discoveries for possible AD.

“ **Philanthropy – gifts of all sizes – has the power to propel the research science to new levels of achievement that would not otherwise be possible.** ”

Participate in one of the Quality of Life Programs

If you or someone you know is interested in participating in one of the SMADRC QoL programs, please contact Tracey Truscott, LCSW for more information. **If you would like to make a donation to support these programs, please contact Laura Adler at (858) 246-1141.**

Thank you!

Make your tax-deductible gift today.

Give a gift to the Shiley-Marcos Alzheimer’s Disease Research Center (SMADRC) through a bequest, retirement account, or appreciated securities.

By Phone:

Laura Adler at (858) 246-1141

Online:

adrc.ucsd.edu/givenow.html

By Check:

UC San Diego Foundation
Attn: Laura Adler
9500 Gilman Drive #0937
La Jolla, CA 92093

Make checks payable to UC San Diego Foundation with “Alzheimer’s research” indicated on the memo line

Staff Updates

Faculty



Sarah Banks, PhD is a clinical neuropsychologist. She is a passionate clinician focused on aging and neurodegenerative disease. In addition she is dedicated to the science of Alzheimer's and specifically how the changes in the brain, detectable with neuroimaging techniques such as PET and MRI, relate to the tests of memory and other thinking abilities used in clinic. Originally from London, she completed her undergraduate degree at the University of Edinburgh, doctorate at Northwestern University in Chicago, internship at the University of Chicago and postdoctoral fellowship at the Montreal Neurological Institute, part of McGill University. Before arriving in San Diego, Dr. Banks led the neuropsychology program at the Cleveland Clinic Lou Ruvo Center for Brain Health in Las Vegas.



Gabriel Léger, MD completed his training in clinical neurology at the Montreal Neurological Institute of McGill University, where he also performed research in imaging of neurodegenerative diseases. He completed clinical fellowships in Movement Disorders at McGill, and in Cognitive and Behavioral Neurology at Northwestern University, Chicago. He returned to Montreal, where he was Assistant Professor and Director of the Neurology Residency program at the University of Montreal. In 2011, he moved to the Lou Ruvo Center for Brain Health of the Cleveland Clinic, Las Vegas, where he directed their fellowship program in Behavioral Neurology and Neuropsychiatry and their frontotemporal dementia (FTD or Pick's disease) and young-onset dementia clinic. He has participated in numerous clinical trials targeting the diagnosis and treatment of Alzheimer's disease and related disorders. In addition, he has special interests and expertise in the diagnosis and treatment of atypical and focal dementias, including FTD, Primary Progressive Aphasia, Posterior Cortical Atrophy, and dementias with Lewy bodies. He joined the neurosciences faculty at UCSD and the ADRC in July 2018.

New Staff



Ivonne Arias, MSW graduated from San Diego State University with a Master's Degree in Social Work. She completed her internship experience at UC San Diego, where she was a Social Work Intern in the Senior Behavioral Health Unit (SBHU), the SMADRC, and the Memory Aging and Resilience Center (MARC). As an intern, she had the opportunity to perform intake evaluations, assist in discharge planning, run various groups with patients, assist with a QoL program, help patients with resources in the community and administer rapid screening assessments. Ivonne is a bilingual, bicultural social worker who became interested in the SMADRC because she is intrigued by neurodegenerative diseases. She currently provides social work services and coordinates participants enrolled in the Young Onset Alzheimer's Disease and Related Dementia's (YoADR) Program.



Bailey Hofmann graduated from the University of Florida Gainesville with a BS in Behavioral-Cognitive Neuroscience. She was previously employed as a research assistant for the UF Social-Cognitive and Affective Development lab with the Florida Institute on Aging where she worked one-on-one with clinical trial participants in administering cognitive and physical functioning tasks. Her field of focus was with cognitive changes in the aging population which fueled her interest in Alzheimer's and other dementias. She currently works as a study coordinator for the longitudinal study SMADRC. In the future, she plans to continue her education by pursuing a PhD.



Shawnees Peacock joined the SMADRC as a Project Assistant in December 2017. She earned her bachelor's degree from UCSD, where she studied Physiology, Neuroscience and Sociology. She previously interned at the Center for Multimodal Imaging and Genetics (CMIG) lab and the Department of Radiology at UCSD to assist with longitudinal research projects focused on both healthy aging and Alzheimer's disease. As a Research Assistant at the CMIG, she collected data using a novel MRI imaging technique designed to be a more sensitive diagnostic. As an outgrowth of her role in this study, she had the opportunity to participate in the Faculty Mentor Program at UCSD to conduct an independent research project that looked at the effects of alcohol consumption on brain microstructure and cognition in older adults. Shawnees currently works in the trials unit at the SMADRC where she coordinates studies related to Parkinson's and Alzheimer's disease.

Trainees



Leonardino Digma "Dino" was born and raised in San Diego. From 2012 to 2016, he sojourned in northern California to study at UC Berkeley. While at Berkeley, Dino completed research in Dr. Bill Jagust's lab and wrote a thesis on the spatial patterns of brain connectivity and amyloid plaque pathology. After receiving his Bachelor of Arts in Neurobiology, Dino moved back to San Diego and joined Dr. James Brewer's lab as a Staff Research Associate in 2016. He is responsible for the processing and analysis of neuroimaging and genetics data at SMADRC. Outside of the research lab, Dino spends time teaching Java programming to kids at the Central Library and searching for the very best burrito and brewery that San Diego has to offer. Dino aspires to be a neurologist and neuroscientist.



Jose Soria-Lopez, MD was born and raised in Cuba before moving to the United States. He completed his undergraduate studies in Biological Sciences at Florida International University in Miami, Florida and obtained his Medical Degree from Johns Hopkins School of Medicine in Baltimore, Maryland. He completed neurology residency training at UCSD and joined the SMADRC in 2018. He is currently furthering his training as a neurology fellow with a focus on neurodegenerative diseases. He is the first bilingual (Spanish/English) neurologist to conduct neurologic evaluations in the observational longitudinal study at the SMADRC.

Social Work Interns



Christian Beltran "Ian" is entering his final year in August 2018 as a Master of Social Work student at California State University San Marcos and is currently a social work intern rotating through the SMADRC. He earned a Bachelor of Arts in Human Development with a Concentration in Adult & Gerontology Services along with a minor in Anthropology at California State University San Marcos. Ian is committed to human service work and has worked in a wide variety of settings, including the American Red Cross as an emergency communication specialist, Alzheimer's San Diego, and the Elizabeth Hospice, where he gained experience liaising with the multidisciplinary medical team and families to schedule patients during a crisis. He last interned with the Oceanside Unified School District as a transformational consultant where he provided school social work services to middle and high school students to address academic performance.



Dominique Hale, MA is currently in her second year of the Social Work Master's program at San Diego State University. Her field internship last year at the Veterans' Home in Chula Vista cemented Dominique's interest in working with older adults. Consequently, she was awarded a student stipend for 2018-19 as part of the San Diego/Imperial Geriatric Education Center's (SDIGEC) Alzheimer's Disease and Related Disorders (ADRD) Masters in Social Work (MSW) stipend program. The mission of this program is to expand training to help develop the next generation of geriatric health workers, including ADRD specialized gerontological social workers. Dominique has a Master's degree in Counseling from the University of Cincinnati and a BA in Literature from UCSD. Dominique's intern experience includes rotations with UCSD's Senior Behavioral Health (SBH) program, the Memory, Aging and Resiliency Clinic (MARC) and SMADRC. She plans to work in the fields of gerontology and ADRD after her graduation in May 2019.

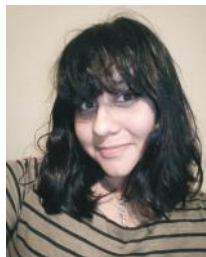
Student Workers



Amanda Calcetas is pursuing a Bachelor's degree at the University of California, San Diego (UCSD) in Cognitive Behavioral Neuroscience with a double major in Clinical Psychology. She is a student worker at the SMADRC contributing to several projects, including Memory Screening data and the enhancement of the registry database. In addition, she works in the Mind and Development Lab at UCSD and conducts experiments investigating intuition, social inferences, and auditory recognition within young children. She is excited to be working with SMADRC because of her interest in interdisciplinary research and how both research and clinical work can benefit individuals with cognitive problems. She will graduate June 2020 and hopes to utilize her experience at SMADRC when she applies to graduate programs for a PhD in the field of neuropsychology.

Staff Updates

Continued



Nancy Gonzalez is studying psychology at University of California, San Diego (UCSD). She started volunteering at the Shiley-Marcos Alzheimer's Disease Research Center (SMADRC) August 2018 then was hired in October as a student worker. Her duties are comprised of the multitude of tasks involved in providing administrative support to the SMADRC team. In the near future, Nancy aspires to get her degree from UCSD and then she plans to join the Navy to become a hospital corpsman to provide treatment to injured military members, veterans and dependents. After the Navy, she hopes to pursue her dream of working with kids with disorders, diseases and syndromes. During her free time, Nancy loves taking a stroll on the beach, babysitting, dog sitting, cooking/ baking, and helping people.



Jade Serrano is a senior at University of California, San Diego (UCSD) studying Global Health. She has been working at Shiley-Marcos Alzheimer's Disease Research Center (SMADRC) since January 2018 assisting with front desk duties, scheduling patient visits, and Latino recruitment. As an aspiring physician, her passion for pursuing medicine is fueled by her desire to serve and advocate for marginalized Latino communities. After graduation, she hopes to continue working at the SMADRC as a bilingual psychometrist during her transition to medical school. During her free time, Jade enjoys cooking, volunteering, being outdoors and making people laugh.

Retiree



Helen Vanderswag, RN, started her nursing career in 1981 and worked in step down units, as well as psychiatry and home care settings. Her career in research at UCSD started in January 1998 in the Geropsychiatry department, housed at the VA hospital. After five years with the Geropsychiatry department there were cuts to the grant that funded the project on which Helen worked. The aphorism, "When one door closes, another one opens," was very true in Helen's situation. A position opened up at the Shiley-Marcos Alzheimer's Disease Research Center (SMADRC) just as she was laid off from the Geropsychiatry department. She started a new career at the SMADRC in July 2003.

Over the 15 years at the SMADRC, Helen worked on over a dozen studies. Although she found Alzheimer's research frustrating because finding the "big cure" remains elusive, she was comforted by the observation that small steps helped to contribute to expand the knowledge base of scientific research. Working in a research setting in the latter part of her nursing career was a wish realized for Helen. Furthermore, being a part of the academic environment of UCSD has nurtured and stimulated her intellectual curiosity.

What Helen enjoyed most during her tenure at UCSD were the people. Not only does she value the collegiate relationships of the investigators and co-workers, she will also always treasure her connection with her participants and their families. She has met and worked with many brave men and women who are willing to give whatever it takes in the name of science. Helen will never forget that dedication.

After almost 21 years of service, Helen officially retired from UCSD on October 6, 2018. How she will spend her golden years remains to be seen. She "plans" not to worry about it! In the meantime, she has three very happy cats enjoying "mom's" company.

Volunteer Opportunity

The SMADRC has a volunteer program for persons interested in assisting our team with a wide variety of activities. Volunteers are an integral component of our outreach and education programs. Students from numerous universities as well as retired professionals are making valuable contributions to projects that fit well with their goals, interests, and talents.

Please contact Tracey Truscott, LCSW at (858) 822-4800 or ttruscott@ucsd.edu for more information if you are interested in learning more.



New Episodes about Alzheimer's Research Available on the UCTV Brain Channel

Thanks to the funds generated from the Soul Cycle fundraiser, coordinated by Genny Matthews and her team, an exciting new opportunity to provide outreach and education is now available to the SMADRC team under the leadership of Dan Bennett, Communications director. The SMADRC is now working with UCTV to create seven new episodes for the UC Department of Neurosciences' Brain Channel (founded by Dr. William C. Mobley), which specializes in episodes devoted to topics that help the viewer discover how the brain works, technologies to harness brain power, ways to treat disease and more. The first two of the seven episodes have already been recorded and are available for viewing online via the Brain Channel links provided below. The first of the two episodes aired in October 2018 and featured an interview with Dr. Douglas Galasko about the genetics of Alzheimer's disease titled, "What Role Do Genetics Play in Alzheimer's-On Our Mind." The second episode, just posted this month, features the first-ever, all Spanish-language episode on the Brain Channel! Dr. Soria-Lopez was interviewed by UCSD psychometrist Alex Figueroa about the investigation of Alzheimer's disease in the Latino community. In this episode, titled "Investigación sobre la Enfermedad de Alzheimer en la Comunidad Latina," the discussion focuses on clinical symptoms and the need to include the Latino community in clinical research. Mention is made of ways to combat the disease and social resources that are available to affected individuals and their families.

More episodes on the way!

<https://www.uctv.tv/shows/What-Role-Do-Genetics-Play-in-Alzheimers-On-Our-Mind-33725>

<https://www.uctv.tv/shows/Investigacion-sobre-la-Enfermedad-de-Alzheimer-en-la-Comunidad-Latina-34205>

The Ongoing Expansion of Community Based Memory Screening

A screening can check a person's memory and other thinking skills. It can indicate if someone might benefit from a more complete medical visit. Systematically assessing thinking abilities as one measure of brain health should be adopted by all seniors in much the same way that blood pressure and cholesterol screening are accepted as part of routine healthcare. The SMADRC has been offering memory screening services for many years at our La Jolla location and will continue to offer this service in an ongoing fashion. In fact, the next offering in La Jolla will be **February 12, 2019. Please refer a friend.**

In addition, we have expanded this program by taking it into the community to several new locations throughout the county to make it more accessible to Spanish speaking elders. The SMADRC is partnering with several not for profit organizations to offer free, 30-minute memory screening assessments that include written feedback to the participants. Ongoing assessments are offered in Chula Vista at the George G. Glenner, Alzheimer's Family Center Town Square, in Little Italy at the Mexican consulate, and in Linda Vista at ACCESS. Following the assessment, participants are given the opportunity to have one-on-one discussions with bilingual ADRC staff members to obtain additional information, gather resources, and discuss research opportunities. Please visit our website for a summary of each offering.

To make an appointment or obtain additional information, please call the Shiley-Marcos Alzheimer's Disease Research Center at (858) 822-4800 or visit adrc.ucsd.edu/MSDevents.html.



UC San Diego
SCHOOL OF MEDICINE
Shiley-Marcos Alzheimer's Disease Research Center

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UPDATES IN RESEARCH AND RESOURCES



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Currents newsletter is supported by the National Institute
on Aging grant P50 AG05131

2019 SERIES

Memories at the Museums



SAN DIEGO MUSEUM OF ART

January 11, May 10,
September 13

MINGEI INTERNATIONAL MUSEUM

Closed for
Renovation

TIMKEN MUSEUM OF ART

March 8, July 12, Novem-
ber 8

MUSEUM OF PHOTOGRAPHIC ARTS

February 8, April 12,
June 14, August 9,
October 11, December 13

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 no cost tour.