

SHILEY-MARCOS ALZHEIMER'S DISEASE RESEARCH CENTER

CURRENTS

UPDATES IN RESEARCH AND RESOURCES



Letter From Our Director, Douglas Galasko, MD

Dear Shiley Marcos ADRC Friends and Families,

In recent months, there has been much in the news about litigation between UC San Diego and University of Southern California surrounding the Alzheimer's Disease Cooperative Study. Many of our Shiley Marcos Alzheimer's Disease Research Center (ADRC) participants, as well as the general public, have expressed understandable confusion about this news and how this might impact our ADRC. We hope the following overview can provide some clarification, and we welcome further discussion with our ADRC families if you have questions.

In 1991, The National Institute on Aging provided funding to UC San Diego to establish the Alzheimer's Disease Cooperative Study (ADCS) with Leon Thal, MD, then director of the Shiley-Marcos ADRC, as its leader. The ADCS was developed to conduct nationwide clinical trials in novel therapies for Alzheimer's disease and the overall administration of these studies has been based at UC San Diego in offices near our Shiley-Marcos ADRC. Upon the sudden and tragic death of Dr. Leon Thal in 2007, Paul Aisen, MD was appointed by the NIA as the new ADCS Director and the administrative oversight of the consortium remained at UC San Diego. Over the 25 years since its inception, the ADCS has initiated and overseen the administration of scores of clinical trials that have been executed at collaborating research centers across the country (and in some cases, international collaborating sites). Our Shiley-Marcos ADRC has been one of the collaborating sites for enrolling participants in ADCS-sponsored clinical trials, but the ADCS and the Shiley-Marcos ADRC are *entirely separate organizations* with distinct missions, administration, funding, and staffing.

Recently, Dr. Aisen was recruited to direct a new University of Southern California (USC) initiative, the Alzheimer's Therapeutic Research Institute (ATRI) that is based in San Diego. Dr. Aisen resigned as director of the ADCS, and several ongoing ADCS-run clinical trials are being transferred to ATRI for administration under this new Institute. Details for transitioning these studies smoothly are being worked out. Meanwhile, the ADCS at UC San Diego continues to coordinate a portfolio of clinical trials, with oversight from the National Institute on Aging.



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Letter From Our Director, Douglas Galasko, MD

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It is important to stress that clinical trials at the Shiley-Marcos ADRC are still up and running and families should rest assured that their participation in any existing studies will continue. We are continuing to participate as a site in the A4 and ADNI trials, which will now be administered by ATRI. Our Shiley-Marcos ADRC is also a collaborating site for many other important investigations into novel therapies for Alzheimer's and related disorders, and we will continue to be a leader in providing clinical trial opportunities for San Diego County families. Please see pages 6-7 for a listing of our currently enrolling clinical trials.

San Diego is a resource-rich region for Alzheimer's services and research and while we can be grateful for all efforts directed to this challenging disease, families may find it difficult to differentiate between the various organizations doing so much good work. To summarize the functions of Alzheimer-related organizations in San Diego, we have provided a basic outline below.

Our efforts at the Shiley-Marcos ADRC reach out to people with Alzheimer's disease and related disorders and their caregivers, and also to people

interested in brain health, aging, and preventing Alzheimer's disease. We hope that the issues underlying the conflicts reported in the news are speedily resolved. In the meantime, we wish to reassure you that our mission, clinical initiatives, and research are continuing strongly, and we remain as dedicated as ever to our partnership with all of you who make our research advances possible.

With warmest regards,
Douglas Galasko, MD
Director, Shiley-Marcos Alzheimer's Disease Research Center.

District Alzheimer-Related Organizations in San Diego

Shiley-Marcos Alzheimer's Disease Research Center

Founded in 1985 at UC San Diego as one of the first of the now 29 NIA-funded Alzheimer's Disease Research Centers in the country. We received additional major funding from Darlene and Donald Shiley in 2004.

Co-Directors: Douglas Galasko, MD and Edward Koo, MD
Location: UC San Diego

Mission: Conduct and support clinical and basic research to investigate the cause, treatment, and prevention of Alzheimer's disease and related dementias. Provide education and support to patients and their families.

Alzheimer's Disease Cooperative Study (ADCS)

Co-founded in 1991 by the National Institute of Aging and Leon Thal, MD (late director of the Shiley-Marcos ADRC).

Interim Co-Directors: William Mobley, MD, PhD and Michael Rafii, MD, PhD
Location: UC San Diego

Mission: The ADCS is a nation-wide coordinating center at UC San Diego, funded by NIA to advance research in Alzheimer's disease clinical trials through a network of sites across the United States.

The Alzheimer's Therapeutic Research Institute (ATRI)

Founded in 2015 as a project of University of Southern California (USC, Los Angeles)

Director: Paul Aisen, MD

Location: Sorrento Valley

Mission: To accelerate the development of effective treatments for Alzheimer's disease through innovative, collaborative, multicenter clinical trials.

Alzheimer's Association, San Diego/Imperial Chapter

Founded in 1982 and is one of now over 70 Alzheimer's Association chapters serving communities across the United States.

President/CEO: Mary Ball

Location: Kearny Mesa

Mission: To eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.

Currents Newsletter Goes Electronic in 2016



Beginning with our Spring issue in 2016, Currents will go out via an email notification that will provide a link to our website where the newsletter will be posted. This switch from a paper to electronic newsletter is just one of the many ways our ADRC is attempting to conserve resources and save money so that funds can be better directed to our research efforts. You are free to print out the newsletter or to forward this link to family or friends, thus making it easier to share Currents and our Shiley-Marcos ADRC activities and updates with others. **We will no longer be providing a printed version of the newsletter.**

PLEASE SEND US YOUR EMAIL ADDRESS by emailing the message: “PLEASE SUBSCRIBE TO CURRENTS” to Beata Santiago at bsantiago@ucsd.edu. Also, you can keep track of our Shiley-Marcos ADRC on our Facebook page at: <https://www.facebook.com/adrc.ucsd>. Look for posts about important updates or research center news, and opportunities to stay updated on the ADRC.

Helpful Federal Resources

Many people may not be aware of the federal efforts directed to research and services in Alzheimer’s and related disorders, as well as longevity and healthy aging. The following websites and organizations provide a wealth of helpful information on all dimensions of aging:

National Institute on Aging

<https://www.nia.nih.gov/>

The National Institute on Aging (NIA) is one of 27 institutes and centers under the National Institute of Health. NIA leads a broad scientific effort to understand the nature of aging and to extend the healthy, active years of life. NIA’s mission is to:

- Support and conduct genetic, biological, clinical, behavioral, social, and economic research on aging
- Foster the development of research and clinician scientists in aging
- Provide research resources
- Disseminate information about aging and advances in research to the public, health care professionals, and the scientific community

You can search the NIA website by health and aging topics from A-Z such as “Arthritis” or “Vitamins” at: <https://www.nia.nih.gov/health/topics>

The NIA also provides a great deal of information for seniors on issues including caregiving; disability; doctor-patient communication; exercise; healthy aging and longevity; and legal and financial planning. Find publications online at the NIA website at: <https://www.nia.nih.gov/alzheimers/publication>

There are also educational materials provided in Spanish under the “Quick Links” tab on this site.

Alzheimer’s Disease Education and Referral (ADEAR)

<https://www.nia.nih.gov/alzheimers>

National Institute on Aging is also the primary Federal agency supporting and conducting Alzheimer’s disease research, including providing a portion of the funding for our Shiley-Marcos ADRC. As such, NIA has a special program devoted to Alzheimer’s and related disorders called Alzheimer’s Disease Education and Referral (ADEAR). ADEAR is a national resource for information specific to dementia and provides a wealth of publications, news about clinical trials, and other resources for families dealing with Alzheimer’s or a related dementia. You can browse their informative website or call ADEAR directly at 1-800-438-4380.

QUALITY OF LIFE PROGRAM UPDATES

“I’m Too Young To Have Alzheimer’s!”

Our NEW Support Group for People with Young-Onset Dementia



When most people think of Alzheimer’s or a related disorder, they assume it is affecting someone who is elderly. Although age is the greatest risk factor for Alzheimer’s, in recent years, scientists and the public have become increasingly aware of people who develop symptoms before age 65. These

individuals range in age from their late twenties to their early sixties and have what is termed “early-onset” or “young-onset” Alzheimer’s. It is estimated that up to 5% of people with Alzheimer’s have younger onset.

Younger individuals and families experience unique challenges. They may be at the peak of a career and earning the money necessary for retirement or other expenses. The onset of disability requires financial and long-term planning. Some individuals may be raising a family with dependent children or young adults still at home or in college. Also, since many social and support programs for persons with Alzheimer’s are primarily directed to older participants, it may be difficult for younger onset individuals or their families to find programs geared to their age group. Although all of these

challenges are significant, there is much more attention being given to young onset families and it is possible to find assistance, build a community, and move forward.

The Shiley-Marcos ADRC has initiated a new monthly young-onset support group to assist individuals who have Mild Cognitive Impairment or early-stage Alzheimer’s or a related disorder to gain new insights and share knowledge and experiences in a safe, supportive environment. The new support group meets on the 1st Thursday of the month from 10:30-12:00 in La Jolla. Pre-registration is required. The group is facilitated by Tracey Truscott, LCSW, clinical social worker at our Shiley-Marcos ADRC. Call 858-822-4800 for more information about this new program or about our other support groups, as well.

My Life Through the Lens

A Photo Taking and Album Making Workshop in Partnership with Museum of Photographic Arts

Last year, The Shiley-Marcos ADRC partnered with the Museum of Photographic Arts (MOPA) to provide a 4-session photography workshop for people with dementia and a caregiver called “My Life Through the Lens.” The workshop was conducted by Kevin Linde, MOPA’s Lifespan Learning Coordinator. Each session of My Life Through the Lens explored discussion of select photographs on a certain theme followed by participants having the opportunity to take photographs related to the theme, print them out,

and then talk about the process. At the end of the four sessions, participants submitted a photo for an album that commemorated the class. Albums were printed and distributed to the participants. All of the materials for this program including cameras, printers, and the final photo albums were very generously provided free-of-charge by MOPA.

We have recently partnered with MOPA to provide “My Life Through the Lens” to Spanish speaking seniors.

We are very grateful to MOPA for their continued generosity as well as their outreach to Spanish speaking seniors with dementia and their families. We intend to continue offering the 4-week “My Life Through the Lens” workshop in 2016 to both English and Spanish speaking participants. If you are interested in being notified of the next program, in English or Spanish, please call the Shiley-Marcos ADRC at 858-822-4800 and ask for Martha Muniz or email her at mcmuniz@ucsd.edu.

All of our Quality of Life programs are provided to the community free-of-charge with no obligation to participate in research.

ADRC Staff News



Many of you may have been acquainted over the years with **Lisa Snyder, MSW, LCSW**, a clinical social worker with us since 1987 and the Director of our Quality of Life Programs. Last year, Lisa was diagnosed with her third round of breast cancer and she went out on medical leave to have treatment. Although her health is now stable, Lisa made the difficult decision to retire this past June in order to slow down the pace of life and maintain her health. She misses her work with the ADRC team and research center participants, but is grateful to have spent so many rewarding years in a field she felt passionate about. She now works from home on a limited basis for the ADRC on select projects, and is trying to practice the self-care she preached to people with dementia and their caregivers over the years!

The ADRC families continue to be a deep source of inspiration for Lisa. She often reflects on the privilege of working with so many extraordinary people who taught her a great deal about resiliency and coping under adversity. You are in her thoughts and heart as she moves forward into this next chapter of life.

Kristoffer Nissinen, MD was born in San Diego, and in his first years moved to Finland where he spent the next 20 years of his life. He moved back to the United States in 2001 to pursue a degree in medicine. He completed his undergraduate studies in Biological Sciences at UCI after which he moved to Arkansas for medical school and obtained his MD from the University of Arkansas for Medical Sciences School of Medicine. He completed his neurology residency at UCI Medical Center and Long Beach VA in the spring of 2011. He is currently furthering his training at the ADRC as a Neurology Fellow with a focus on memory disorders and neurodegenerative diseases, which includes working with patients in clinical practice and clinical trials. In his spare time he enjoys gardening, playing the guitar, walking, and cooking.



Rick Seghers was raised in New Orleans, Louisiana. He moved to San Diego in 2003 to work for UCSD as the Research Protocol Coordinator for the HIV Neurobehavioral Research Center, a multi-study research group investigating the causes and effects of neurobehavioral disturbance associated with HIV infection and/or substance abuse. In 2006 he moved to Dallas Texas to work as the Data/QA Manager and Research Study Coordinator as well as Assistant Clinical Research Manager at the University of Texas Southwestern Medical Center for the HIV Research Unit. In 2008 he moved back to San Diego and returned to a position at UCSD as the SR. Community Program Representative at UCSD's HIV Neurobehavioral Research Programs & Translational Methamphetamine AIDS Research Center.

In 2014 he accepted a position at Moore's Cancer Center as the North County Clinical Trials Coordinator and in 2015 he accepted a position with UCSD's Shiley-Marcos Alzheimer's Disease Research Center as a Clinical Research Coordinator.

Vanessa Candare is a Certified Clinical Research Coordinator for the Alzheimer's disease clinical trials. She joined the Shiley-Marcos ADRC in 2015 after working with UCSD's Clinical and Translational Research Institute on vascular surgery, infectious disease, women's health, and Alzheimer's trials. Vanessa grew up in San Diego and moved to Okinawa, Japan in 1997 for 5 years. Vanessa returned to San Diego in 2002 and earned her undergraduate degree in Psychology at the University of California San Diego. She is currently going back to school to pursue a master's degree as a Physician Assistant.



Clinical Trials for Persons with Normal Cognition

A4: ANTI-AMYLOID IN ASYMPTOMATIC AD

PRINCIPAL INVESTIGATOR: Douglas Galasko, MD | **TIME INVOLVED:** 3 years
CONTACT: Christina Gigliotti, PhD (858) 822-4800 or cgigliotti@ucsd.edu

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, with a study partner
- Normal cognition
- MRI and PET scans required
- Lumbar puncture optional

CIRM: CALIFORNIA INSTITUTE OF REGENERATIVE MEDICINE

PRINCIPAL INVESTIGATOR: Douglas Galasko, MD | **TIME INVOLVED:** 1 visit
CONTACT: Christina Gigliotti, PhD (858) 822-4800 or cgigliotti@ucsd.edu

This study will obtain a blood sample, and in some cases a skin sample, from older adults with normal cognition to make pluripotent stem cells that can be reprogrammed into nerve or other cells to study Alzheimer’s disease mechanisms.

REQUIREMENTS:

- Age 65 and older, with a preference for persons 75 and older

COGNITIVE AGING LONGITUDINAL STUDY (ALSO AVAILABLE IN SPANISH)

PRINCIPAL INVESTIGATOR: Douglas Galasko, MD
TIME INVOLVED: Minimum 5 years
CONTACT: Christina Gigliotti, PhD (858) 822-4800 or cgigliotti@ucsd.edu

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
- Normal cognition
- Study partner
- LP and MRI required
- Brain autopsy required

STEM CELLS DERIVED FROM SKIN FIBROBLASTS

PRINCIPAL INVESTIGATOR: Douglas Galasko, MD
TIME INVOLVED: One time only
CONTACT: Christina Gigliotti, PhD (858) 822-4800 or cgigliotti@ucsd.edu

The purpose of this study is to study mechanisms of brain aging by deriving neurons from skin biopsies. A small piece of skin is removed from the forearm, the cells are grown in a dish, and induced to become neurons.

REQUIREMENTS:

- Age 65 and older
- Normal cognition
- Study partner

Clinical Trial for Mild Cognitive Impairment

MERCK 19: EPOCH - PRODROMAL AD TO AMCI

PRINCIPAL INVESTIGATOR: Shauna Yuan, MD

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

CONTACT: Christina Gigliotti, PhD 858-822-4800 (cgigliotti@ucsd.edu)

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
- MMSE > 24

Clinical Trials for Alzheimer's Disease

CIRM: CALIFORNIA INSTITUTE OF REGENERATIVE MEDICINE

PRINCIPAL INVESTIGATOR: Douglas Galasko, MD | **TIME INVOLVED:** 1 visit

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

This study will obtain a blood sample from persons with Alzheimer's disease to make pluripotent stem cells that can be reprogrammed into nerve or other cells to study Alzheimer's disease mechanisms.

REQUIREMENTS:

- Able to come in for one time appointment to have blood drawn

STEM CELLS DERIVED FROM SKIN FIBROBLASTS

PRINCIPAL INVESTIGATOR: Douglas Galasko, MD | **TIME INVOLVED:** One time only

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

The purpose of this study is to study mechanisms of brain aging by deriving neurons from skin biopsies. A small piece of skin is removed from the forearm, the cells are grown in a dish, and induced to become neurons.

REQUIREMENTS:

- Study Partner
- One time appointment for skin biopsy

NOBLE: TOYAMA TCAD (T817)

PRINCIPAL INVESTIGATOR: Shauna Yuan, MD

TIME INVOLVED: 12 visits in 14 months

CONTACT: Vanessa Candare (858) 657-1299

Drug is neurogenic/neuroprotective. 4 pills administered once/day. 2/3 get study drug; 1/3 at low dose, 1/3 at high dose. Open label guarantee for an additional 28 weeks.

REQUIREMENTS:

- Age 55-85
- MMSE 12-22
- Must be taking Aricept or Exelon patch at least 6 months
- 2 MRIs or CTs
- 2 optional lumbar punctures

EMERGE: BIOGEN (BIIB037)

PRINCIPAL INVESTIGATOR: Douglas Galasko, MD **TIME INVOLVED:** 2 years

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

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
- MMSE 24-30
- Study partner
- PET and MRI scans
- Able to have monthly infusions

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SHILEY-MARCOS ALZHEIMER'S DISEASE RESEARCH CENTER

University of California, San Diego
9500 Gilman Drive -0948
La Jolla, CA 92093-0948
(858) 822-4800
<http://adrc.ucsd.edu>

Co-Directors:
Douglas Galasko, MD
Edward Koo, MD

Program Director:
Mary P. Sundsmo, MBA

Editors:
Christina Gigliotti, PhD
Lisa Snyder, LCSW

Layout Design:
Yada Khoongumjorn

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2015 SERIES

SEE OUR WEBSITE FOR THE 2016 SCHEDULE!



SAN DIEGO MUSEUM OF ART

January 9, May 8,
September 11

MINGEI INTERNATIONAL MUSEUM

February 13, June 12,
October 9

TIMKEN MUSEUM OF ART

March 13, July 10,
November 13

MUSEUM OF PHOTOGRAPHIC ARTS

April 10, August 14,
December 11

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 required. Please call Tracey Truscott, LCSW at the Shiley-Marcos Alzheimer's Disease Research Center at (858) 822-4800 to register for a tour.