

SHILEY-MARCOS ALZHEIMER'S DISEASE RESEARCH CENTER

# CURRENTS

UPDATES IN RESEARCH AND RESOURCES



## Caregiving During COVID

By Sierra Adkins\* and Pamela De Leon Aguilera\*, MADURA Scholars, and Paula Desplats, PhD (\*equal contributors)

The COVID-19 pandemic grabbed much of the world by surprise, and we all had to endure an unthinkable reality, where isolation was the first line of defense from one of the most serious health threats of our time. People living with dementia and their families suffered as social isolation affected both their mental and physical health.

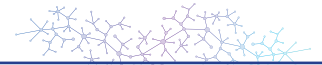
Science has made stunning achievements in the fight against this deadly virus, including the development and massive administration of several effective vaccines so far. California recently lifted most of the pandemic-associated restrictions, and locally, the San Diego area approached the much-anticipated milestone of herd immunity, with more than 70 percent of the population over 12 years old already immunized. Despite tentative steps toward “normal,” families are still in a recovering mode, defining new approaches and safe behaviors, while others are coping with the irreparable loss of family and community members.

In this article we explore the impact of COVID-19 among our community of patients with dementia and their families, share first-hand stories from caregivers themselves and provide some additional resources for caregivers to cope with the increased stress.

## Myrna's Story

“My name is Myrna. My mom was the caregiver for my father, who was diagnosed with Parkinson's and dementia when he was in his late 80s. Throughout his 50s, he was very active and enjoyed sports, but he reached a point four years ago where my mom, Myrna, could no longer care for him by herself. He was moved to a care home and my mom visited my dad, Fred, several times a day, every day. She helped Fred with his feeding, cleaning and doing his laundry until the pandemic hit. We visited him through the window of the care home with signs for him to read and communicate with. We were happy to care for him and look after him even at the care home because we enjoyed cheering him up and putting a smile on his face. We learned a lot about changes associated with Parkinson's disease and other dementias. We couldn't have done it without support and resources. The Shiley-Marcos Alzheimer's Disease Research Center holds a special place in our hearts. My dad has been involved since 1993 and he would participate in studies or tests. I cannot stress [enough] the importance of participating ... to contribute to Alzheimer's and other neurodegenerative diseases research.”

*continued on page 2*



## Caregiving During COVID *continued from page 1*

### Effects of Pandemic on Patients

Patients with dementia living both at home and in care facilities are confronting unprecedented levels of social isolation and high mortality risk by way of the novel coronavirus, as the pandemic has taken an undoubtable psychological, physical, and emotional toll on them.

In a July 2020 survey of caregivers of loved ones with Alzheimer's and related diseases living in care facilities, conducted by UsAgainstAlzheimer's, more than 9 in 10 report they were unable to visit their loved one due to visitation restrictions. Because dementia patients often don't fully understand the scope of the pandemic, it is likely they feel abandoned by their family and may withdraw from those around them. Since the pandemic began, overall stress levels have increased and one person with dementia told UsAgainstAlzheimer's, "I feel like I'm hanging on by a thread mentally."

Evidently, the longer the periods of isolation, the more severe neuropsychiatric symptoms are experienced. This chronic feeling of loneliness is linked to both poorer mental and physical health, and consequently higher mortality. With respect to development of other dementia symptoms, caregivers have noticed a faster rate of decline in their loved ones and many now require 24/7 care. Additionally, it is much more difficult for people with dementia to follow CDC guidelines to wear a mask and maintain social distance. This contributes to care homes having excessively high rates of infection and reinforcing the need for extreme lockdown measures to further isolate the patients living there.

Conditions are improving, however. The rate of COVID cases in California has significantly decreased in the past few months and scheduled visitations are allowed in care facilities that have not had an active outbreak within the past 14 days. With a growing majority of the California population being fully vaccinated, we can more comfortably visit people living with a dementia diagnosis in hopes of bolstering their psychological state.



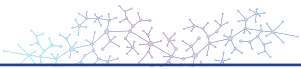
### Effects of Pandemic on Caregivers

In a study of the impacts of COVID-19 on family caregivers, the results showed that, according to Innovative Aging, "Caregiver effects included increased isolation, higher stress, loss of support, neglected health needs, and accelerated technology adoption." Almost all dementia caregivers have experienced fear about spreading COVID-19 to the person they are caring for, and have exhibited one or more symptoms of anxiety.

Dr. Maria Carrillo, an Alzheimer's Association chief science officer, notes, "Most likely, dementia does not increase risk for COVID-19, just like dementia does not increase risk for the flu. However, dementia-related behaviors, difficulty following safety protocols, increased age and common health conditions that often accompany dementia may increase risk."

The UsAgainstAlzheimer's (UsA2) A-LIST conducted a survey in March 2020 to find impacts of the novel coronavirus on caregivers for people living with Alzheimer's or mild cognitive impairment (MCI). This survey included responses from more than 800 people affected by Alzheimer's disease and other dementias—including patients with a diagnosis as well as family caregivers. Particularly, one of the major hurdles in this group was uncertainty about the care of the patients, in the event that either they or the caregiver contracted COVID-19. "Alzheimer's family caregivers are frontline healthcare workers in their home, and if they get sick, what happens to the patient?" said Meryl Comer, a long-time caregiver for her husband and mother, and UsA2 founding board member. "Family caregivers already had higher levels of loneliness and isolation, and the coronavirus restrictions have made them even more isolated from family and friends, more stressed and more concerned about their future financial health."

Another consequence of COVID-19 on caregivers is significantly increased stress. High levels of stress have been associated with concerns about their financial health and their family's finances since even before the pandemic. Spending days on end with their loved ones also contrib-



uted to frustration, while additional tension built up as activities outside of the home were largely curtailed. As expressed by a responder whose spouse has dementia, “She cannot understand why we can no longer go to places (library, restaurants, etc).”

On the other hand, individuals whose loved ones have been in assisted living facilities during the pandemic have also suffered heightened levels of stress, associated with restricted visits and the inability to monitor the level of care their parents or spouses were receiving. Despite these concerns, half of the respondents opted for assisted-living placement as they felt unprepared or lacked the resources to provide a safer option for care amidst the pandemic.

## How to Cope as a Caregiver

Caring for someone with dementia or a related disease can be challenging and sometimes overwhelming. Certain feelings might be more prominent now, due to prolonged COVID-related limitations on other outlets, or simply not knowing how to cope with emotions that arise.

It can be hard to navigate this new reality, in which a person with dementia might manifest severe behavioral changes that are beyond anyone’s control. One thing caregivers do have control over is how they approach the situation when frustrated. As noted by the Family Caregiver Alliance, “In order to respond without extreme frustration, you will need to: learn to recognize the warning signs of frustration, intervene to calm yourself down physically, modify your thoughts in a way that reduces your stress, learn to communicate assertively, and learn to ask for help.”

Some warning signs of frustration include headaches, compulsive eating, lack of patience, and desire to strike out. To calm down, the best option is to temporarily walk away from the situation to collect one’s thoughts. Caregivers can try listening to music, calling a friend or taking a few deep breaths. In regards to modifying thoughts, caregivers should not focus on negative situations or overlook good situations; nor should they assume or jump to conclusions. Effective communication can make the difference between understanding or misunderstanding each other. A very important step is to ask for help and know when to say yes



and when to say no. Caregivers have multiple responsibilities and should not feel guilty for saying “no” to a situation or request.

Support groups are crucial tools for maintaining the mental health of caregivers for people with dementia. Support groups are usually led by trained professionals that facilitate the opportunity for caregivers to share their feelings and experiences, and gain emotional support. As a result of the pandemic, many support groups are now held online. Some groups have seen more continuous participation as the virtual format provides some needed flexibility around caregivers’ hectic schedules. For more information about support groups or to sign up, visit the Shiley-Marcos ADRC’s website.

## Cause for Cautious Optimism

Since the COVID-19 pandemic spread to California in March 2020, the United States has been dealing with the unforeseen challenges of social distancing, wearing masks, and practicing isolation.

Despite some positive trends over the summer, according to Johns Hopkins University, in which California was seeing fewer than 1,400 new cases a day and almost 60 percent of the state’s population became fully vaccinated, cases are once again soaring with the arrival of COVID-19’s Delta variant. As hospitalizations also rise, primarily of people who have not been vaccinated, the importance of inoculations cannot be emphasized enough.

With the increased protection from the vaccine, families and friends can now visit their loved ones living with dementia and bring back their spirits.

Still, it is of crucial importance for caregivers to take care of themselves, to not only provide and care for their loved one but also be a healthy example to those around them. It’s important to know the signs of fatigue or extreme frustration, so caregivers can identify them and seek help when needed. As the worst of this pandemic is hopefully over, we are amazed by the endurance of this community and the incredible strength and love of caregivers and families who flourish amidst the adversity.

\*Caregiving resources available on the SMADRC website at [adrc.ucsd.edu](http://adrc.ucsd.edu).



## Online Conference Reviews Pivoting During the Pandemic: Biopsychosocial Considerations in Neurodegeneration

By Riley Ellis, SMADRC undergraduate volunteer

On June 2, 2021, the Shiley-Marcos Alzheimer's Disease Research Center collaborated with our partners at the Alzheimer's Disease Resource Center for Minority Aging Research (AD-RCMAR) to hold a virtual continuing medical education conference. Titled "Pivoting During the Pandemic: Biopsychosocial Considerations in Neurodegeneration." Presenters addressed the timely theme of pandemic-related implications for research and practice. Six faculty members from UCSD and SDSU (Dr. Dilip Jeste, Dr. Ellen Lee, Dr. Camille Nebeker, Dr. Linda Gallo, Dr. Howard Feldman, and Dr. Douglas Galasko) presented to an audience of clinicians and researchers to discuss the biopsychosocial impacts of COVID-19 on the brain, the implications for clinical practice, and the effects on research involving patients with neurodegenerative diseases. To supplement the live presentations, four UCSD researchers (Dr. Elizabeth Bevins, Dr. Anne Hiniker, Dr. Ariana Stickel, and Dr. Zvinka Zlatar) pre-recorded content for the attendees. Those presenters shared their expertise on topics including reversible dementias, subjective cognitive decline, whether common risk factors for neurocognitive decline apply to Latinos, and clinical pathological correlation case presentations.

Dr. Howard Feldman's presentation specifically focused on treatment and prevention of Alzheimer's disease during the pandemic. He reviewed the literature regarding the impact of COVID-19 on patients with dementia and also included a segment about how administration of clinical research has adapted during COVID-19. He presented the increased risks of COVID-19 for those with dementia, explaining that patients with dementia were more likely to experience delirium, but less likely to experience other common COVID-19 symptoms such as chills and nausea; additionally, COVID-19 patients with dementia died earlier

in their hospital course and had significantly lower overall survival than patients without dementia. Dr. Feldman discussed a number of risk factors beyond dementia that would increase the likelihood of presence and severity of COVID-19 illness.

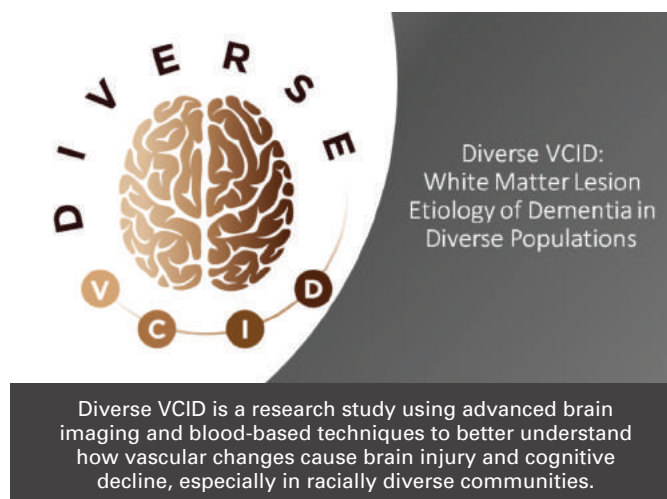
These impacts were exacerbated by health disparities, therefore they especially affected people of color and those who live in low-income communities. Latino and Black patients, for example, were less likely to receive telestroke services during the pandemic; Black patients with AIS had higher morbidity than white, Asian, or Latino patients, and low-income patients with Parkinson's disease had worse access to health care during the pandemic than patients with higher incomes.

Despite the negative impacts of COVID-19, Dr. Feldman explained that public trust in the vaccine was still fairly low. Dr. Feldman attributed this continued distrust of COVID-19 vaccines to people fearing the long-term side effects, disdain for public health officials, lack of trust in the government, and the spread of misinformation about the vaccine.

Dr. Feldman continued by acknowledging the challenges that the COVID-19 pandemic posed to researchers. He applauded the SMADRC's ability to adapt to these changes. In order to maintain the validity and efficacy of the ongoing clinical trials under new CDC public health guidelines, researchers enacted a number of adaptations. They implemented the use of weekly phone calls to remind participants to self-report in activity logs, expanded the participant enrollment to home-based activity, gave all trials the ability to be attended virtually, and added telehealth visits, Zoom meetings, and more enrolling sites for increased communication with patients.

## New Neuroimaging Studies Underway at the SMADRC

The Shiley-Marcos Alzheimer's Disease Research Center (SMADRC) is pleased to be participating in a new multi-site, National Institutes of Health–funded study, called Diverse VCID: White Matter Lesion Etiology of Dementia in Diverse Populations. The purpose of this research is to better understand how vascular health and abnormal white matter signals in brains affect people's thinking. The term “vascular” refers to the blood vessels, while white matter is brain tissue made up of nerve fibers that allow brain cells to quickly send and receive messages. White matter hyperintensities (WMH) can show researchers that there is damage to the blood vessels in a patient's brain (vascular brain injury). This can result in something called vascular cognitive impairment and dementia (VCID). WMH result from injury to small blood vessels in the brain, which are important for moving oxygen and nutrients to cells of the brain. Results from this study will improve physicians' understanding of how poor vascular health causes WMH and VCID. We hope that these findings will lead to treatments aimed to reduce VCID.



If you are between the ages of 65 and 90, note a decline in your memory or thinking over the last three years, and are of African American, Hispanic/Latino, or European ancestry, you may be eligible for participation. Your participation in this research will involve three visits and will last about three years. Participation in this study will involve

completing three physical, neurological, and cognitive examinations, blood draws, and brain MRIs. Participants who are already enrolled in the longitudinal study will not have to repeat any of the physical, neurological, or cognitive tests. The brain MRIs and a few additional questionnaires and assessments will be the only additional requirements beyond those that current participants already engage in annually in that study. Participants will be compensated for their time and travel for each visit with a \$100

gift card upon completion of the visit.

If you are interested in participating or learning more, please contact Lilly Pacheco at [lpacheco@ucsd.edu](mailto:lpacheco@ucsd.edu) or (858) 822-4800.

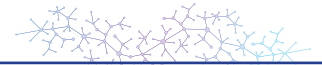
## SCAN: The Standardized, Centralized, Alzheimer's and Related Dementias Neuroimaging (SCAN) Program

The Shiley-Marcos Alzheimer's Disease Research Center (SMADRC) is collaborating with the National Institute on Aging (NIA) to participate in the Standardized, Centralized, Alzheimer's and related dementias Neuroimaging (SCAN) program. This program is designed to support standardized imaging in an effort to improve the biomarker characterization of the UC San Diego SMADRC clinical cohort. New and emerging availability of imaging and biofluid markers of Alzheimer's disease (AD) now permits a more complete assessment of underlying neuropathology within living individuals. As such, modern studies of AD and related dementias (ADRD) in human subjects increasingly rely on biomarker characterization of cohorts to stage disease and to reduce contamination from clinical mimics. The SMADRC will ensure that de-identified raw scans are provided to the National Alzheimer's Coordinating Center (NACC) for sharing with qualified investigators.

For many years, researchers at the NIA-funded Alzheimer's Disease Research Centers have been collecting different

types of PET and MR images of their research participants. These data, which researchers call “legacy data,” were collected using different acquisition methods. Because of this, image data could not be simply combined across centers, resulting in lost opportunities for scientific collaboration. The goal of SCAN will be to promote standardization of PET and MR image acquisition so that images can be combined across multiple centers. These prospectively acquired images will be subject to standardized quality control procedures, then uploaded to NACC where they will be appropriately archived, labeled, and made available to qualified investigators.

Select participants enrolled in the SMADRC Observational Longitudinal Study will be invited to participate in imaging protocols using both MRI and PET scanners. For more information about neuroimaging procedures, visit the SMADRC website to read fact sheets and see the Brain Blast video available on the SMADRC's YouTube channel, at [youtube.com/UCSDShileyMarcosADRC](https://youtube.com/UCSDShileyMarcosADRC).



## Observational Studies

For a complete listing of enrolling studies, visit the SMADRC website: [adrc.ucsd.edu](http://adrc.ucsd.edu)

### **COGNITIVE AGING LONGITUDINAL STUDY (ALSO AVAILABLE IN SPANISH)**

**PI:** Douglas Galasko, MD

**CONTACT:** Tracey Truscott, LCSW (858) 822-4800 or [ttruscott@ucsd.edu](mailto: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. It does not involve an intervention. 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 cerebrospinal fluid (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; lumbar puncture (LP) and magnetic resonance imaging (MRI) required; brain autopsy required.

### **THE ALLFTD STUDY**

**PI:** Doug Galasko, MD

**CONTACT:** Ivonne Arias, MSW (858) 822-4800; [imarias@ucsd.edu](mailto:imarias@ucsd.edu)

**DESCRIPTION:** ALLFTD goal of better understanding Frontotemporal Lobar Degeneration (FTD). The study will track the changes that happen in brain function as a result of disease progression, and will help to develop new tools to assist with diagnosis. Study is enrolling patients with FTLD syndromes, typically involving changes in behavior, language, or movement, as well as healthy family members when several people in a family have FTLD or there are FTLD-associated genetic mutations. Participants who are symptomatic or "at risk" may participate in ALLFTD. This is an observational study, meaning that at this time, ALLFTD does not provide drug therapies, but study coordinators may be able to provide referrals to pharmaceutical partners who are testing interventional medications.

The ALLFTD Study: [allftd.org](http://allftd.org)

FTD and Resources YouTube Video: [youtube.com/watch?v=HypqiSzQ](https://youtube.com/watch?v=HypqiSzQ)

### **EVOKED RESPONSE POTENTIALS**

**PI:** James Brewer, MD, PhD

**CONTACT:** Nichol Ferng, [nferng@ucsd.edu](mailto:nferng@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 EventRelated Potentials (ERP) have shown promise in small studies, but no study has examined how they compare to other markers. 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. Visits will occur once every three years for all subjects

**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; good general health. MRI, PET scan, and EEG.

### **ALZHEIMER'S DISEASE NEUROIMAGING INITIATIVE 3 (ADNI)**

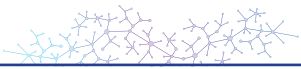
**PI:** James Brewer, MD, PhD

**CONTACT:** Nichol Ferng, [nferng@ucsd.edu](mailto:nferng@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. 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; normal cognition or a diagnosis of MCI or AD; a study partner; overall good general health. Subjects are required to undergo MRI and PET scans and a lumbar puncture.



## Intervention Trials for MCI and Early Alzheimer's Disease, and Other Dementias

A clinical trial is a research study in which a human subject is assigned to one or more interventions (which may include an investigational drug, placebo or other control) to evaluate the effects of those interventions on health-related or behavioral outcomes. When you volunteer to take part in clinical research, you help doctors and researchers learn more about disease and improve health care for people in the future.

The ADRC Clinical Trials Unit has a variety of clinical trials available for participants with Alzheimer's disease and related dementias. We add new studies to our portfolio regularly and encourage individuals who are interested in participating to reach out to the ADRC. Studies currently in the pipeline that will be starting recruitment in the near future include:

### PEACE-AD

Phase 2b clinical trial of the drug prazosin in Alzheimer's disease. The goal of the PEACE-AD study is to identify a well-tolerated treatment for people with severe agitation in the later stages of Alzheimer's disease. The total length of the trial is 22 weeks.

**MAIN REQUIREMENTS:** Participants must be experiencing agitation that disrupts their daily life; the participant must reside home with full-time caregiving and have a primary caregiver who participates as a study partner.

### JANSSEN

Phase 2 study aiming to slow the progression of prodromal and mild Alzheimer's disease by preventing the propagation of tauopathy. The length of the trial is up to

4.5 years.

**MAIN REQUIREMENTS:** Age 55-80; evidence of pathological tau on a screening PET scan

### ALZHEON ALZ-801

Phase 3 study aiming to inhibit amyloid aggregation into toxic oligomers. The length of the treatment is 78 weeks. The study drug will be orally administered.

**MAIN REQUIREMENTS:** Age 50-80; early stage of Alzheimer's disease; carriers of the APOE4/4 genotype

### ALECTOR AL001-3

Phase 3 study for individuals at risk for or with frontotemporal dementia due to mutations in the progranulin gene. This study will provide genetic testing for individuals with a family history who may be eligible to participate. The

length of trial ranges from 48 to 96 weeks depending on the treatment condition.

**MAIN REQUIREMENTS:** Age 18-85; carriers of heterozygous loss-of-function progranulin gene (GRN) mutations

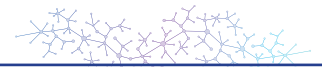
### DISCOVER:

Phase 1b study of Posiphen, which may have a potential to delay the onset or slow the progression of Alzheimer's disease via decreased amyloid production. This study will investigate whether Posiphen is safe and tolerated. This short-term study is up to two months and will require at

least five study clinic visits, including a three-day stay at UCSD clinical research unit.

**MAIN REQUIREMENTS:** Age 55-89; MMSE 17-30; diagnosis of MCI or mild Alzheimer's disease

Please contact Nobuko Kemmotsu, PhD, at [clinicaltrialsADRC@health.ucsd.edu](mailto:clinicaltrialsADRC@health.ucsd.edu) or (858) 246-1267 to learn more about clinical trials.



## Subjective Cognitive Decline and Risk for Alzheimer's Disease in Hispanic/Latinx Individuals

By Zvinka Zlatař, PhD

The term “subjective cognitive decline” refers to a person perceiving that their memory or thinking abilities have worsened over time. Subjective cognitive decline may be an early risk marker of preclinical Alzheimer's disease in some individuals, but this is not the case for everyone who experiences it. Therefore, it is important to identify who may develop Alzheimer's disease if they experience subjective cognitive decline. We do not know how subjective cognitive decline manifests in Hispanic/Latinx older adults or if it increases the risk of Alzheimer's disease over time.



Since Hispanic/Latinx individuals have higher risk of developing Alzheimer's disease compared to those who are not Hispanic/Latinx, we are trying to understand if subjective cognitive decline is related to memory and thinking changes in this population. This study will investigate whether subjective cognitive decline is associated with changes in memory and thinking abilities over three years and with proteins commonly seen in Alzheimer's disease. It is very important to identify early risk markers of Alzheimer's

disease in the Hispanic/Latinx community so we may intervene early and provide adequate treatments to prevent changes in memory and thinking.

We are actively recruiting participants for this study. To participate, you must be 60 years of age or older, not diagnosed with dementia or Alzheimer's disease, identify as Hispanic/Latinx, speak English and/or Spanish, and have a loved one who can participate with you. Our staff is bilingual and bicultural, and the study can be conducted in the language of your preference. There will be three annual appointments

over three years. We will ask participants to answer some questionnaires, complete cognitive testing, and provide a blood sample during these yearly visits. Their loved ones will be asked to complete some questionnaires. Participants will receive up to \$120 and their loved ones up to \$75 for completing all study visits. We can help with transportation costs and parking permits are available. If you are interested, call the [WISE Lab](https://www.health.ucsd.edu/wise-lab) at (858) 822-7737 or email us at [wiselab@health.ucsd.edu](mailto:wiselab@health.ucsd.edu).

## Staff Updates

### Welcoming two new bilingual staff members to our SMADRC team!



**Jocelyn Vargas** recently graduated from UC San Diego with a degree in Applied Mathematics and a minor in Psychology. During her time at UCSD, she volunteered as a bilingual research assistant in Dr. Tamar Gollan's language production lab, which led her to discover an interest in research and psychology. Her interest in neuropsychology specifically developed while taking a class to

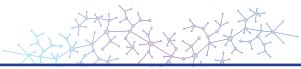
learn more about the effects of injury to the brain due to a personal experience. She is now a bilingual psychometrist at the SMADRC. In the future, her goal is to find a way to combine her math degree and interest in research.



**Antonio (Tony) Gama** has been in the medical field for over 20 years. Tony received his Medical Assistant and Phlebotomy Certification in 2000 and earned an AS degree in Allied Health in 2012. Tony began his medical career with Navy Medicine as a civilian and worked with Navy Medicine for over 17 years. Tony's experience includes working with such clinical departments as pediatrics,

podiatry, and sports medicine, as well as in urgent care, laboratory, and clinic settings. Tony has been teaching phlebotomy at U.S. colleges since 2012, and he has won Instructor of the Quarter multiple times for Best Student Retention and Highest NHA Pass Rate.





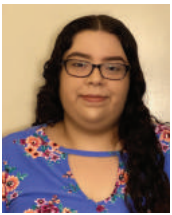
## The MADURA Student Scholars Working With the SMADRC

The MADURA Program, focusing on Mentorship for Advancing Diversity in Undergraduate Research on Aging, is a training opportunity funded by the National Institutes of Health's National Institute on Aging.



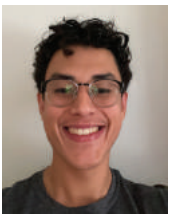
**Diep Thanh Ngoc Nguyen**  
**Major: Public Health, with concentration in Medicine Sciences**  
**Graduated: June 2021**

The MADURA program has given me insight about geriatric medicine and how researchers conduct studies. Neurodegenerative diseases such as Alzheimer's and Parkinson's have become common in our society and impact our loved ones. I enrolled in the MADURA program because I want to learn more about Alzheimer's, how to prevent it and how to detect it at an early age.



**Priscilla T. Gonzalez**  
**Major: Human Biology**  
**Expected graduation: June 2022**

As a Latinx first-generation transfer student, I did not have the support to conduct research. MADURA provided me the opportunity to work alongside a mentor and be introduced to fundamentals of scientific investigation. As a future physician, my participation in MADURA will allow me to gain knowledge regarding the signs, causes, and treatments of neurodegenerative illnesses. I have experienced the emotional toll that neurodegenerative diseases cause loved ones, as my grandma and aunt battled the disease. Thanks to MADURA, I am gaining skills needed to investigate the mechanisms behind neurodegenerative diseases and other health issues affecting my community.



**Alonzo Mendoza**  
**Major: Public Health**  
**Expected graduation: 2022**

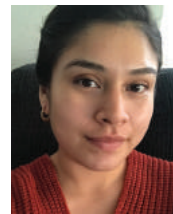
I enrolled in the MADURA program to gain experience in the research field, see what careers are available to me, and to gain new mentors that can help me develop professionally. Although I have only been in the program for two quarters, I have learned a lot and am really grateful for the learning experience and mentors I have gained along the way.



**Sierra Adkins**  
**Major: Human Biology**  
**Minor: Psychology**  
**Expected graduation: June 2023**

The MADURA program has opened my eyes to the idea that not everyone's career path is linear and to be open to exploring all avenues

of medicine, as well as introducing me to diseases of the brain. MADURA has also provided me the opportunity to work with a remarkable mentor, Dr. Paula Desplats, along with several others in the lab. I am grateful to be a part of this program that heavily stresses community and mentorship, and I look forward to applying the skills I am learning throughout my journey with medicine.



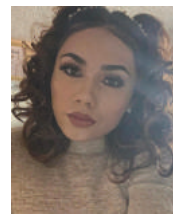
**Pamela De Leon**  
**Major: Human Biology**  
**Expected graduation: June 2022**

The MADURA program has allowed me to explore different career options within aging and Alzheimer's disease work that I was unaware of. I have learned a significant amount of information about Alzheimer's disease under the guidance of Dr. Paula Desplats. MADURA has sparked my interest in neuroscience and I intend to learn more about Alzheimer's disease, dementia, and our aging population as I pursue a career in medicine. I am thankful for the mentorship and opportunities I have received through MADURA.



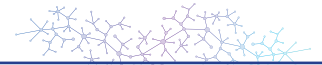
**Andrew Torres**  
**Major: Neurobiology**  
**Expected graduation: June 2022**

I applied to the MADURA program to be exposed to many opportunities and experiences that I would otherwise not be able to attain on my own. This is exactly what the MADURA program has provided for me and more. I was also able to meet many amazing colleagues through my placement with MADURA as well as many amazing patients that come through the research center where I was placed. The work that I have done with my research center has shown me all the amazing work that goes into Alzheimer's research and I am very grateful for this opportunity.



**Montserrat Rodriguez**  
**Major: Human Biology**  
**Expected graduation: Spring 2022**

Through MADURA, I was able to find excellent mentorship. I found my true passion for research and have now narrowed down my future career options. I have gained new skills and believe this practice and new knowledge will help me achieve my goal of getting into graduate school.



## Ask the Experts: Aduhelm

By Dana Soriano, SMADRC undergraduate volunteer

Experts from UCSD's Shiley-Marcos Alzheimer's Disease Research Center hosted a live Q&A session via Zoom recently to discuss the FDA's decision to approve a new treatment for Alzheimer's disease. During the forum, Dr. James Brewer, Dr. Howard Feldman, and Dr. Gabriel Leger explained perspectives about the effectiveness and approval of Aduhelm (generically known as aducanumab).

The U.S. Food and Drug Administration recently granted conditional approval of Aduhelm via an accelerated approval pathway reserved for drugs that treat serious diseases with reasonable potential to impact the course of illness. Aduhelm is a monoclonal antibody that parallels the immune system's mechanism of targeting and removing foreign particles. This drug is delivered to the blood monthly at an infusion center, and specifically removes amyloid proteins from the brain. Physicians will now have access to prescribing the new amyloid therapy but many obstacles impacting the drug's delivery remain unaddressed: distribution to pharmacies, availability of infusion centers, and funding for the drug (estimated to cost \$56,000 per year for the medication alone). The decision to undergo this treatment requires a partnership between the patient, their family, their neurologist, and their primary care physician, as it is a very personal decision that requires thorough education on the drug's risks and potential benefits.

The ambivalence toward Aduhelm stems from the unclear causal relationship between protein deposition and cognitive decline as well as the discrepancies found in the results of the drug's clinical trials. Although amyloid is one of the two main proteins associated with the development of Alzheimer's disease, and PET scans from clinical trials consistently support the drug's ability to remove amyloid

from the brain, full linkage between the deposition of this protein and cognitive decline still remains unclear—which contributes to the skepticism about Aduhelm's effectiveness as a treatment. Experts highlighted that removing amyloid from the brain does not directly translate to a clinical benefit for patients; it is not guaranteed that cognitive decline will slow solely due to the removal of amyloid in the brain. The inconsistent Clinical Dementia Rating (CDR) trends of Aduhelm's Engage and Emerge clinical trials also give rise to further hesitance. The CDR provides a quantification of individuals' cognitive and everyday function; a high CDR represents poor functioning. The CDRs for all Engage and Emerge groups continued to increase during the trials' 78 weeks, but the ratings of Emerge treatment participants were lower, with a statistically significant difference compared to participants who received placebo medication. The same trend was not observed in the Engage participants, who underwent the same treatment. The FDA decided to overrule the statisticians who recommended that the collected data was not strong enough to gain approval, thus Aduhelm's conditional approval was based on its ability to consistently remove amyloid in the brain, rather than the drug's influence on cognitive and everyday function.

Before Aduhelm, the last treatment for Alzheimer's disease was approved 20 years ago. Despite clinical trials data not being as strong as desired, the collected Emerge and Engage data has been the most promising since then. Experts are hoping for the long-term benefit of clearing amyloid from the brain as a viable Alzheimer's disease treatment.

A recording of this event is available on our YouTube Channel at [youtube.com/UCSDShileyMarcosADRC](https://youtube.com/UCSDShileyMarcosADRC).

**Q:** How long does treatment last?

**A:** Dr. Feldman: Though the medication label did not describe when to stop treatment, it is likely that Aduhelm will follow the protocol of another monoclonal antibody treatment called donanemab. Donanemab is not administered for the rest of one's life; amyloid therapy is halted once amyloid in the brain is gone. Clinicians must carefully judge how long to provide Aduhelm.

**Q:** Are there serious side effects?

**A:** Dr. Leger: Aduhelm does come

with risks. When there is more amyloid in the blood vessels than anticipated, this medication can create leaky blood vessels that can progress into swelling and bleeding in the brain. Mild symptoms include headache, nausea, and dizziness, but these can be minimized with the appropriate dose.

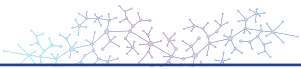
**Q:** Where should I go to receive this treatment?

**A:** Dr. Feldman: This treatment will require an infusion center, careful follow-up, and access to imaging

services. At the moment, we are not specifically aware of which sites will offer this medication but hopefully nationwide access will unfold.

**Q:** How can I find out if my insurance covers the cost?

**A:** Dr. Brewer: The decision of whether Medicare will cover the cost of this treatment has yet to be finalized, but it is likely that patients will still be subjected to the 20 percent copay, which makes the cost at least \$11,000 per year for patients who do not have additional coverage.



## The Power of Philanthropy: Meet Denis Smirnov

By Dana Soriano, SMADRC undergraduate volunteer

Denis Smirnov, one of ADRC's outstanding MD/PhD students, celebrates the end of his PhD journey by reflecting on his transformative years of unparalleled opportunities and unique research he was able to pursue at the ADRC. He started his journey with freedom that was made

possible by philanthropic funds and donations; he was not tied to a premade project or forced to work with a specific person. The money raised by the center allowed him to explore his own ideas and collaborate with experienced pathologists, neuropsychologists, and clinical neurologists that would not have been possible in a smaller lab

setting. This freedom created a chance for Smirnov to familiarize himself with the center's resources and connections which served as the training he needed to compose his own grant to fund the concluding years of his PhD.

Earlier this year, Smirnov defended his doctoral dissertation on "Clinicopathologic Studies of Alzheimer's Disease and Related Dementias." He explored the atypical manifestations of pure Alzheimer's disease in combination with the ambiguity behind a myriad of understudied related dementias. His research findings reiterate the urgent need to develop criteria to distinguish between these conditions. Smirnov hopes that his dissertation can contribute to further specifying the diagnosis process and ultimately provide the appropriate treatments to those experiencing cognitive impairment.

### Ways to Give Your Philanthropy - Where Breakthroughs Begin

At the Shiley-Marcos Alzheimer's Disease Research Center (SMADRC), philanthropic support creates limitless possibilities in scientific learning, exploration and discovery that can transform lives.

Your support for our Spanish language research is especially meaningful. Latinos are disproportionately affected by neurocognitive disorders. To shift this disparity, we actively recruit participants from these diverse populations to increase our knowledge of this major public health problem and to prevent or delay milder forms of dementia from evolving into severe disease.

Contributions to our work advance this groundbreaking research helping to mitigate early neurocognitive disorders in populations who may be at increased risk of impairment. We couldn't do it without you.

Gifts of all sizes play an important role in sustaining our momentum. The innovative, inclusive research by SMADRC's faculty and early career investigators is making a real impact on human health and well-being thanks to the essential support from our donor community.

Please help us in propelling our next breakthrough!

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Kim Wenrick at (858) 735-5137  
or [kwenrick@ucsd.edu](mailto:kwenrick@ucsd.edu)

### BY THE NUMBERS

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**151**

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**26**

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## Virtual Memories at the Museum

**Live Zoom • 2:00 to 3:00 p.m.  
First Tuesday of every month**

**Trained docents provide interactive tours to participants with memory disorders and their care partners at exceptional museums in Balboa Park.**

Participants are given opportunities for meaningful engagement in developmentally appropriate activities that are carefully designed to support the varying experience and ability levels of each individual in a group setting to facilitate success and socialization.

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in collaboration with the Alzheimer's Association



San Diego Museum of Art  
Mingei International Museum: Closed for renovation until 2021  
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Museum of Photographic Arts

Pre-Registration is required at <http://smadrc.eventbrite.com>