

MoND Matters

A quarterly publication of UCI MIND

Fall 2018

GRAND OPENING OF UCI SLEEP CENTER



In 2016, UCI recruited esteemed sleep medicine physician, Dr. Ruth Benca (left), to serve as the Chair of the Department of Psychiatry and Human Behavior. Dr. Benca, who is also a UCI MIND faculty member, has conducted critical research to understand the role of sleep

in mental health and brain disease, including the relationship between sleep and the biology of Alzheimer's disease.

While revitalizing the Department of Psychiatry in her brief time here, Dr. Benca has been steadily increasing the clinical and research capacity at UCI toward the study of human sleep. In September, a major milestone in this effort was achieved with the opening of UCI's new state-of-the-art Sleep Center at 20360 Birch Street in Newport Beach, a short drive from main campus. The 6,500 square-foot center (right) is modeled after the world-

renowned sleep center at University of Wisconsin, Madison, that Dr. Benca previously directed. Dr. Benca's vision is to modernize sleep medicine by utilizing multimodal physiological monitoring to transform how we understand sleep and its importance to healthcare. While this center will substantially increase the availability of cuttingedge sleep medicine services for the people of Orange County, it will also increase the capacity for novel research into the relationship between sleep and brain disease.



Wine for the MIND

Leadership Council member, Virginia Naeve, and her husband Bob graciously hosted the 5th annual Wine for the MIND kickoff event benefiting UCI MIND's *A December to Remember* gala on **December 1, 2018**. Guests donated fine wines to be auctioned at the gala and engaged in rich discussion with UCI MIND clinicians and scientists about the latest advances in Alzheimer's disease research and current innovative projects at UCI. To learn how you can directly support the leading-edge research taking place at UCI MIND, join researchers and philanthropists for the annual gala. Event information and tickets are available online: **gala.mind.uci.edu**.



Researchers and friends of UCI MIND raise a glass to the success of A December to Remember gala (Photo credit: Stan Sholik).

FROM THE DIRECTOR



Dear Friends of UCI MIND,

As we enter the season of giving, UCI MIND continues to increase its attention toward philanthropy. We do this, despite the fact that Congress recently increased funding for Alzheimer's disease (AD) research and UCI MIND faculty continue to be highly successful in securing federal grant dollars. You may ask why. The answer is simple—because the need to discover new ways of diagnosing, treating, and preventing AD and related conditions is too great not to expedite our research by every means possible.

Philanthropic support remains vital to the mission of UCI MIND. It funds transformative translational research, like that being performed by Dr. Ruth Benca and her team at

the new UCI Sleep Center (page 1). Their work could unlock keys to understanding how sleep removes toxic proteins associated with AD from the brain and means to improve that process. Philanthropy is also critical to support the training of the next generation of AD clinicians and scientists. UCI MIND is extremely proud of the talented trainees who have chosen to pursue careers in dementia research, like the six outstanding graduate students and postdoctoral fellows serving as co-chairs of our trainee organization, REMIND (page 3).

We are fortunate to have extraordinary supporters at UCI MIND (pages 6-7). These benefactors have enabled cutting-edge research that otherwise would have been delayed or never occurred. New friends, like Greg and Cindy Lai (page 5), have helped create opportunities to grow our network of supporters. And we will honor some of our longest, most passionate, and most impactful supporters at our annual *A December to Remember* gala this year (pages 1 and 8).

There are many ways to support UCI MIND's mission. Philanthropy is vital, but advocacy is also critical. And in the end, only through volunteers enrolling in studies will we solve the crisis of AD. That is why the gift given by Gwen Ritchie and her mother, who together enrolled in a clinical trial at UCI MIND, is as important as any we receive (page 4). AD is the most important medical problem we face as a society today. We are honored to have so many partners in the fight to rid the world of this disease and to research ways to *Make Memories Last a Lifetime*.

Trials Today, Treatments Tomorrow

UCI MIND and Alzheimer's Orange County co-hosted the 29th Annual Southern California Alzheimer's Disease Research Conference on World Alzheimer's Day, September 21. Over 350 physicians, nurses, psychologists, social workers, and community members, as well as representatives from 40 local senior service organizations attended the conference at the Irvine Marriott Hotel to collaborate and learn what it is going to take to develop improved treatments for Alzheimer's disease (AD).

A remarkable panel of expert speakers, including faculty from Cleveland Clinic Lou Ruvo Center for Brain Health, University of Pennsylvania, Johns Hopkins, Rush University, Mount Sinai, and UCI MIND addressed the field's progress toward improved treatments and preventions for AD. Topics included the history of AD drug development, clinical trial design, pharmacologic and nonpharmacologic interventions, prevention in cognitively healthy older adults, and a novel perspective on redefining AD. Additionally, a panel of research

participants and study partners (right), including Gwen Ritchie (page 4), shared their honest motivations, challenges, and experiences with clinical trial participation.

UCI MIND would especially like to thank this year's Platinum Sponsor, SCAN Health Plan, for its support of the conference. If you were unable to attend, videos of each presentation can be found on UCI MIND's website and YouTube channel:

www.mind.uci.edu/events/conference www.youtube.com/user/UCIMIND



MEET THE REMIND CO-CHAIRS

REMIND is a campus organization led by UCI MIND predoctoral and postdoctoral trainees that aims to encourage collaboration among the next generation of scientists and clinicians and to promote community outreach and education on neurodegenerative diseases. UCI MIND is pleased to introduce this year's REMIND co-chairs:



Alessandra Martini, PhD
earned her doctorate in
Pharmacology from the
Federal University of Santa
Catarina in Brazil. In Dr. Frank
LaFerla's lab, she studies
how inflammation plays a
key role in the development
and progression of

Alzheimer's disease. Alessandra believes direct engagement between scientists and the public is critical to promote trust and create a better future for all of us. She hopes to create a better understanding of neuroscience research, fostering creativity and excitement about science to children and adults alike.



Ashley Keiser, PhD
earned her doctorate in
Biopsychology from the
University of Michigan. In
Dr. Marcelo Wood's lab, she
studies sex differences in
the effects of exercise on
learning and memory using
Alzheimer's disease mouse

models. As a first-generation college student who found it difficult to discover research pathways, Ashley hopes to provide knowledge on research and career opportunities to diverse groups of people and to inform those who have been affected by memory disorders.



Morgan Coburn completed her bachelor's degree in Neuroscience and Behavior with a Chemistry minor at Mount Holyoke College. In Mathew Blurton-Jones' lab, she examines the role of microglia, the innate immune cells of the brain, in

Alzheimer's disease pathogenesis. Her work aims to discover how genetics and the immune system contribute to Alzheimer's disease, which could lead to the design of immune targeted therapeutics and gene therapies. As a co-chair, Morgan looks forward to engaging in community outreach and education about current research.



Amanda McQuade
completed her bachelor's
degree in Molecular, Cellular
Neuroscience at Scripps
College. In Dr. Mathew
Blurton-Jones' lab, Amanda
studies how the immune
system plays a role in the
progression of Alzheimer's

disease. She uses stem cell technology to improve understanding and develop improved treatments for Alzheimer's disease. Amanda believes scientists have a commitment to share their research with the community and looks forward to working with local school districts, adult audiences, and individuals with Alzheimer's disease.



Sarah Royer earned her bachelor's degree in Neuroscience at The Ohio State University. In Dr. Aileen Anderson's lab, Sarah studies aging and inflammationinduced changes in neurogenesis.

As a past REMIND co-chair, Sarah helped develop an educational partnership with local K-12 schools in collaboration with the Beall Center for Art + Technology. She hopes the partnership will increase understanding and inspire excitement about science.



Michelle Nuno completed her bachelor's degree in Applied Mathematics at the University of California, Riverside. In Dr. Daniel Gillen's lab, she focuses on developing improvements in statistical methods to better analyze data from Alzheimer's disease

biomarker research and clinical trials.

As a co-chair, Michelle hopes to spark the interest of young students in science and careers they may not have otherwise considered.

STUDY PARTNERS IN ALZHEIMER'S DISEASE RESEARCH



Today in the United States, More than 16 million people are providing unpaid care to a person with Alzheimer's disease (AD). Caregivers are most often adult daughters of a parent with the disease, and are also frequently working mothers raising children of their own. They may be working full-time or part-time to support their family or may have been forced to leave a job due to the increasing demands of caring for a loved one with the disease. Gwen Ritchie is one such woman who, in addition to caring for her mother with AD, is raising three boys with her husband, is working part-time, and is committed to participating in clinical research at UCI MIND. All clinical research studies for AD require enrollment of two people – a participant and a study partner. Study partners play critical roles in research, helping make sure study visits are attended but also providing critical information about how the person with AD is doing cognitively and in their daily activities. As an adult child study partner, Gwen represents an under-represented group in AD research. It can be difficult for adult children to find the time to participate. But, to find preventative and therapeutic treatments faster, we must enroll more people like Gwen and her mother. So, we interviewed Gwen to learn more about her experience as a study partner:

What motivated you to participate in clinical research with your mom?

First, I participated to benefit my mom. I wanted to take a chance on a new drug that might help her. If she were assigned the placebo, I liked that this clinical trial allowed her to receive the test drug in the last six months of the study. Also, the timetable was reasonable – one visit every two months was workable with my schedule. And doing this for the greater good was huge. My mom was diagnosed with AD in 2013, along with four of her six siblings. So, it's pervasive in my family. I'm passionate about trying to do my part to help find a cure or some kind of medication for the next generation.

How do you juggle family life, work life, caregiving, and participating in research?

It's super hard to balance everything. I literally set aside days for my mom, days for my kids, and days for myself and my marriage. We are so fortunate to afford in-home caregivers who help with my mom most days of the week. Daily, I manage their payroll and schedule, as well as my mom's medications and doctor visits. We average over 40 visits a year for her care! On Wednesdays, my mom and I attend a floral arrangement class together (above). It's something that she can do that we both enjoy. I'm 57 years old and also have to be careful of my own health. I don't want to live the next 10 years just caring for my mom and getting sick myself. So, I attend Pilates classes weekly, spend time with kids and granddaughter, and make

time for ski trips with my husband. It takes a village to care for one person with AD, and I am fortunate to have family support and wonderful caregivers. Without all the extraordinary love and help, we would not be able to care for my mom as well.

As a study partner, what does a typical research visit look like?

Before the visit, my mom has to fast. This has been extremely difficult for her, so I have to monitor her before visits to ensure she complies. When we get to the center, the research team takes me to one room for an interview and my mom to another room for blood and cognitive testing. Visits typically take two to three hours, and my mom gets irritable from all the time spent answering questions and completing procedures. So, I try to make it fun by taking her to lunch after each visit.

What has been the most challenging aspect of being a study partner?

For the clinical trial, my mom has to take the dosage twice a day in the morning and evening within a half hour of eating, and she does not like to cooperate. So, making sure she takes the medication (or placebo) and explaining why she has to take it twice a day has been challenging. There was definitely a learning curve in the beginning, but it was okay once I got into the groove of it. I've also had some challenges scheduling our study visits, but I have not cancelled once. I understand how important it is to attend visits.

(continued on next page)

STUDY PARTNERS IN ALZHEIMER'S DISEASE RESEARCH (continued)

What has been the most rewarding aspect of being a study partner?

I think the drug is working. We're now in the last six months of the trial where she has had the opportunity to take the drug. I believe she was previously on the placebo because she seems to be doing much better now, having lucid moments that I have not seen in years! I don't know if I'll ever find out whether she was taking placebo or drug, but it would be interesting to know.

What is one piece of advice you would give to people like you who are considering research participation?

First, make sure it's a credible institution conducting the study. I get asked to join studies from different organizations all the time, and I don't have time to research them. I knew right away that this study at UCI MIND would be credible because the referral came from my mom's neurologist who we trust. Next, I would say to make sure the study fits into your life

- how much time will it take on a daily basis and can you even integrate it into your life? When considering this clinical trial, I felt it was a reasonable amount of time, doable for my schedule. When people drop out, it hurts the progress of the study, so make sure you can do it.

Why do you think it is important to participate in Alzheimer's disease research?

It's humbling to know the research team is trying to figure out this horrible disease for me and for future generations. The first few years after my mom's diagnosis were extremely difficult, such dark days. Now, with the right combination of support, guidance, and doctors, I feel hope. I'm happy I was able to make a lifestyle change to participate in research with my mom, and I'd do it all over again. It brings hope and joy to my life that we're doing something proactive for my mom's illness instead of being reactive. People dealing with this disease can barely get through the day, and I'm lucky I can afford the time.

Philanthropist Highlight

On September 13, members of the UCI Merage Dean's Leadership Circle gathered to learn the latest in Alzheimer's disease (AD) research from UCI MIND Director, Dr. Joshua Grill, at an event hosted by Greg and Cindy Lai (right). Greg is the chair of the Dean's Leadership Circle in the Merage School. When he first learned about UCI MIND, he was motivated to help promote the inspiring progress being made in the fight against AD happening right here in Orange County. Rather than wait for someone else to step in, Greg and his wife, Cindy, offered to host an educational gathering in their home. At the event, Dr. Grill along with UCI MIND researchers, Drs. Frank LaFerla, Mathew Blurton-Jones, Stefania Forner,



Alessandra Martini, and Lindsay Hohsfield, discussed the latest developments in AD research. Attendees were particularly interested in the cost and challenges of developing new treatments for AD and learned how philanthropy can help accelerate progress. During the event, Greg shared, "Cindy and I are proud to support UCI MIND. They are making a real difference in the fight against Alzheimer's. The disease is affecting our family and we want to do what we can to help." As an interdisciplinary research institute, UCI MIND is proud of its partnerships across campus and grateful to Greg and Cindy Lai for their leadership and commitment to UCI.

As you think about year-end giving, where will your generosity take you?



With the holidays upon us and your thoughts turning to year-end giving, you might want to consider making a gift of long-term appreciated assets. Stocks and real estate are an easy and tax-wise way to make a more impactful charitable gift because you can:

- Bypass capital gains
- Reduce income tax liability
- Make a substantial gift to charity

For more information on how gifts of stock or other appreciated assets can support UCI MIND, call **949.824.3251**.

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MIND Matters is a publication of the UCI Institute for Memory Impairments and Neurological Disorders in collaboration with the Alzheimer's Disease Research Center (ADRC) and the California Alzheimer's Disease Center (CADC). The ADRC is funded by a grant from the National Institute on Aging and supports and promotes interdisciplinary research on Alzheimer's disease. The CADC is funded by the California Department of Public Health and provides expert clinical assessments and diagnosis of memory complaints related to Alzheimer's disease and other dementias.

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