# MoND Matters

A quarterly publication of UCI MIND

Fall 2017

### **NEW GRANTS AWARDED FOR CUTTING-EDGE SCIENCE**

Through the hard work of many advocates and stakeholders, including UCI MIND scientists, patients, caregivers, and research participants, Congress again increased research funding for Alzheimer's disease in fiscal year 2017. The funding climate remains uncertain, but UCI MIND investigators are wasting no time in securing opportunities to fund new and exciting projects.



(from left) Andrea Wasserman and Drs. LaFerla, Baglietto-Vargas, MacGregor, Mortazavi, Green, and Tenner

Several applications notable for their size and scope are worth highlighting. UCI MIND co-director Frank LaFerla and Drs. Andrea Tenner, Kim Green, Grant MacGregor, Marcelo Wood, and David

Baglietto-Vargas were awarded an \$11 million grant to create the next generation of mouse models to study Alzheimer's disease. UCI MIND is already home to the discovery of the first ever mouse model to develop both amyloid plaques and neurofibrillary tangles, the two hallmark pathologies of Alzheimer's disease. Created by Dr. LaFerla's laboratory, this model was based on genetic mutations that cause the rare young-onset inherited form of the disease. The new grant will

allow UCI MIND investigators to take knowledge gained over the years to create a more accurate model of the common, older onset "sporadic" form of Alzheimer's disease. Such developments will be key to rapid testing of promising therapies and preventions, with improved translational potential for predicting outcomes in human testing.

In 2015, Dr. Ira Lott and colleagues were awarded \$37 million to dramatically increase the understanding of Alzheimer's disease biomarkers in Down syndrome (see Winter 2016 MIND Matters). Dr. Lott and his team were recently awarded an additional \$16 million toward this large and important study to add the latest and greatest biomarker, tau positron emission tomography (PET) imaging. This work includes Dr. Lott's long-standing research coordinator Eric Doran, along with collaborators Drs. David Keater and Mike Yassa.

Dr. Yassa, along with Data Management and Statistics Core leader Dr. Dan Gillen, were recently funded to add similar biomarkers, high-resolution magnetic resonance imaging (MRI) and amyloid PET imaging, to UCI MIND's Longitudinal Study. In addition, Dr. Craig Stark received funding to perform magnetic resonance spectroscopy on participants in this key cohort.

(continued on page 4)

Bin Nan, PhD Professor of Statistics

### **New Faculty Investigators**

UCI MIND is pleased to welcome new faculty members Bin Nan, PhD, and Bryce Mander, PhD. Dr. Nan received his doctorate in biostatistics from the University of Washington in 2001 and then joined the faculty of the University of Michigan. His research focuses on epidemiology, bioinformatics, and brain imaging in neurodegenerative diseases.

Dr. Mander received his doctorate in neuroscience from Northwestern University and completed his postdoctoral fellowship at the University of California, Berkeley. He has published many important findings on the relationship between sleep quality, memory in older adults, and Alzheimer's disease pathology.



Bryce Mander, PhD Assistant Professor of Psychiatry and Human Behavior

### FROM THE CO-DIRECTORS



Dear Friends,

As the holidays approach, it is an excellent time to look back over the year and take stock. We at UCI MIND have much for which we are thankful.

As outlined on page 1, the growing national recognition of the importance of Alzheimer's disease research has produced new opportunities for funding. And UCI MIND faculty are well positioned to capitalize on these opportunities and bolster our portfolio of important and cutting-edge research.

We have also seen our faculty grow this year, with the addition of outstanding scientists, Drs. Bin Nan and Bryce Mander (page 1). Both are

valuable additions to the UCI MIND team, bringing added expertise in biostatistics and the neuroscience of sleep, respectively. We also look forward to hiring additional faculty members in the coming year to further grow our multidisciplinary expertise. Two searches for new faculty are currently underway.

In addition to new faculty, we are grateful to welcome a new friend and partner, Maria Shriver, to our upcoming gala on December 2 (page 5). Ms. Shriver is a tireless advocate for Alzheimer's disease research, and we are excited to begin what we hope will be a long and productive relationship with her organization, The Women's Alzheimer's Movement.

But most importantly, we are grateful for the incredible men and women who give their time and energy to help advance Alzheimer's disease research at UCI MIND. In this issue, we highlight two such individuals, Jerry Leth (page 3) and Steve O'Leary (page 4), as well as the generous community members and organizations who have donated to UCI MIND over the past year (pages 6-7). With your support, our important work toward ridding the world of Alzheimer's disease and related disorders is made possible. Thank you, and happy holidays.

### The Elephant in the Room: Sensitive Subjects in Dementia Care



Speakers answered questions from audience members at the close of each session

UCI MIND and Alzheimer's Orange County hosted the 28th Annual Southern California Alzheimer's Disease Research Conference on Friday, September 22. Esteemed speakers from Brown, Stanford, UCLA, UCSF, USC, and UCI addressed sensitive topics such as driving risk and Alzheimer's disease, elderabuse, sex and intimacy, end-of-life decisions, and suicide. Following heartfelt introductory videos from caregivers on each topic, speakers confronted challenges faced by many with Alzheimer's disease in an effort to reduce stigma and facilitate a safe space for conversation among healthcare providers, patients, and families. Over 400 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 how to better address the needs of the 84,000 people living with Alzheimer's disease in Orange County.

UCI MIND would especially like to thank this year's Diamond 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 at www.mind.uci. edu/events/conference and www.youtube.com/user/UCIMIND. Speakers Fay Blix, Esq, and Drs. Ruth Benca, Lynn Flint, And stay tuned for announcements of next year's fall conference.



and Brian Ott participated on a Q&A panel about suicide and the California End of Life Option Act

### RESEARCH PARTICIPANT HIGHLIGHT

Jerry Leth is a research participant in an Alzheimer's disease prevention clinical trial at UCI MIND. He was recruited to the clinical trial through the UCI Consent-to-Contact (C2C) Registry, an online tool developed by researchers at UCI MIND to help match adults in Orange County with new, cutting-edge clinical studies at UCI. The goal is to help researchers cure life-threatening illnesses faster with the help of volunteer community members, like Jerry.

In this interview, Jerry shares why he joined the C2C Registry and what motivates him to participate in research.



Jerry Leth with wife Betsy

### Why did you decide to enroll in the C2C Registry?

Last November, my neighbor invited me to attend a presentation by Dr. Frank LaFerla. He mentioned the critical need for research participants and the C2C website (c2c.uci.edu) where I could sign up to learn about studies I might qualify for. So I thought, what do I have to lose? I have good friends who have Alzheimer's, and we're all living longer, so the probability of getting the disease is increasing. If there's something I can do to delay it, that would be great. If I could help researchers find a prevention, why not? Wouldn't it be great to come up with something that resolves Alzheimer's disease?

### What did you expect when you enrolled?

I was beginning to wonder why I wasn't contacted right away. I signed up in November and wasn't invited to participate in a study until March. I know now that it may take some time or a person may never be contacted if they don't qualify. The point is to sign up anyway to help researchers quickly find people who do qualify. That will help speed up the process of finding results.

# What did you think when you were invited to participate in an Alzheimer's clinical trial?

I thought, great! I had an idea that there would be some interviews and some qualifications I would need to meet. When I came to the research center for the first time, I got a better picture of what the study was all about. The research team was very informative and helpful. Once I learned more about the study, like the risks and procedures involved, I made the decision to continue.

### Why did you decide to participate in the trial?

It was the money! (laughter) No, it was a sense of purpose, the feeling that maybe I can help. I don't know whether this study is going to be successful. But, I pray that it is because there are so many people affected by this disease. If I can help people continue to have productive, meaningful lives as they age, why not? I hope that at the end of the study, researchers are going to be able to say, we got something here! We learned something and here's what we can do.

# What has been the most challenging aspect of participating in research?

The only challenge in the beginning was considering the risks. But, I was able to take time to talk to my primary care doctor and make an informed decision. Otherwise, there hasn't been anything challenging about it.

# What has been the most rewarding aspect of participating in research?

I feel like I'm helping people, so that's rewarding. I don't know whether this study will be successful or not, but I can say that I tried and made a difference because researchers will learn something from this.

# What is one piece of advice you would give to people considering enrolling in the C2C Registry?

I'd say it's very low risk, it helps researchers, and the inconvenience of participating in a study is very minor compared to the positive results it could create. And we need more people to get involved so we can create positive results. Can you imagine a world where there is no Alzheimer's and related diseases? That's the vision that motivates me.

### PHILANTHROPIST HIGHLIGHT



Steve and Patty O'Leary

Steve O'Leary brings new meaning to the term philanthropy. Steve's wife of 47 years, Patty O'Leary, was diagnosed with Alzheimer's disease in 2012 and passed away in February of this year. Patty participated in research at UCI MIND, donating her time and ultimately her brain to help researchers gain a better understanding of the disease. Steve accompanied Patty to study visits and sought support through a men's caregiver group he started with his friend and fellow UCI MIND Leadership Council member, Keith Swayne.

Still, as Patty's disease progressed, Steve wanted to do more. So, he harnessed his expertise in marketing to help raise awareness of UCI MIND. "You get to a point where you're trying to find out ways of contributing to finding a solution to this disease," said

Steve, "If there's a way for me to do something and make a difference, I'm more than on board."

And his dedication has proven invaluable. Steve has been instrumental in the launch of the UCI C2C Registry and is responsible for recruiting a highly respected PR agency, Brower, Miller & Cole, to promote the cutting-edge work taking place at UCI MIND, pro bono. In addition, Steve delivers presentations to local community groups to help raise awareness of the disease and the importance of research participation.

Steve's contributions, both monetary and volunteer, have increased momentum for Alzheimer's disease research recruitment, which will help UCI MIND investigators find improved treatments and preventions faster.

Steve's story is an admirable example of the many ways individuals can support Alzheimer's disease research at UCI MIND. If his story inspires you, we invite you to support UCI MIND as you consider your year-end giving. Please use the enclosed envelope to return your donation in any amount or visit www.mind.uci.edu/donate to submit your contribution securely online.

For questions, contact Linda Scheck, Director of Development, at **949.824.3251** or **lscheck@uci.edu**.





## LOOKING FOR 'RESEARCH HEROES'

Steve featured on the front page of the OC Register for his participation in the UCI C2C Registry

### **NEW GRANTS AWARDED FOR CUTTING-EDGE SCIENCE**

(continued from page 1)

Dr. Mathew Blurton-Jones received two major grants to continue his work using induced pluripotent stem cells to understand disease mechanisms, especially as they relate to nonneuronal cells in the brain. Finally, Drs. Claudia Kawas and Maria Corrada were funded on multiple collaborative applications to increase understanding of brain pathology in the oldest-

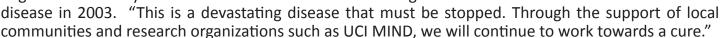
old and to better understand the role of race and ethnicity in dementia in this fastest growing segment of our population. These many funded applications reflect the collective expertise and innovative ideas of UCI MIND faculty. Given the opportunity, our scientists are eager to do as much as possible in the fight against Alzheimer's disease and related disorders.

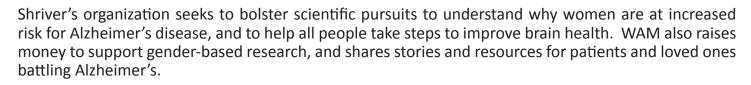
# MARIA SHRIVER, CELEBRITY HONOREE FOR 8TH ANNUAL "A DECEMBER TO REMEMBER" GALA

Maria Shriver, internationally renowned Alzheimer's disease advocate, founder of The Women's Alzheimer's Movement, and former First Lady of California, will be honored at UCI MIND's 8th annual A December to Remember gala on **Saturday**, **December 2**, **2017**.

"Maria Shriver is a champion for Alzheimer's disease research and a voice of strength for many families and individuals who are suffering as a result of this disease," says Dr. Joshua Grill, co-director of UCI MIND. "We are proud to partner with Ms. Shriver and honor her important work that continues to shine a light on Alzheimer's disease." Shriver is the founder of The Women's Alzheimer's Movement (WAM), a global alliance of individuals, organizations, researchers and industry leaders who are committed to studying Alzheimer's disease and why it disproportionately affects women.

"Every 66 seconds a new brain develops Alzheimer's. Two-thirds of them belong to women, and no one knows why that is," explains Shriver, who began her advocacy for the cause when her father was diagnosed with the





Dr. Frank LaFerla, Dean of UCI's School of Biological Sciences and co-director of UCI MIND, notes that Orange County is particularly susceptible to the pressures of Alzheimer's disease. "The number of people in Orange County living with Alzheimer's disease is going to increase 74% by the year 2030," Dr. LaFerla explains. "The only way to avert this crisis is through research, which is precisely where the proceeds from this event will be applied."

With support from the local community, UCI MIND funds projects that allow researchers to seek out scientific advances that will help identify ways to prevent or slow the onset of neurological disorders like Alzheimer's.

"Thanks to the tremendous generosity of our attendees, last year's gala raised over \$375,000 to support innovative research on new studies and clinical trials," says Dr. LaFerla. "This year, we've extended an invitation for guests to attend an exclusive pre-event cocktail reception with Maria Shriver prior to the gala, along with various unique sponsorship opportunities that we hope will continue to support our research efforts surrounding Alzheimer's disease."

UCI MIND is one of only 31 NIH-funded Alzheimer's Disease Research Centers in the nation. "The research being done at UCI MIND provides hope for millions of individuals who are affected by this heartbreaking disease," Grill adds. "It's through attending events like our annual gala or participating in clinical research that Orange County residents can, in fact, make a difference and help researchers get closer to a cure."

For more information about the 8th annual *A December to Remember* gala, or to inquire about sponsorship opportunities, please visit **gala.mind.uci.edu** or contact Linda Scheck, Director of Development, at **949.824.3251** or **lscheck@uci.edu**.



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EDITORS: Joshua Grill, PhD Chelsea Cox, MPH, MSW

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