

MIND Matters

SPRING 2020

SPECIAL FEATURE

Adapting to change in the wake of COVID-19

The COVID-19 pandemic has made life challenging for many, none more than families facing Alzheimer's disease and related dementias.

News media reports provide a daily reminder of the disproportionate impact of COVID-19 on American nursing homes, where many people with dementia reside and receive care. In the home, people with dementia may have difficulty adhering to safer-at-home guidelines and other public health recommendations to protect themselves and others from infection. And of course, quarantine has placed additional burdens on caregivers, who are having to adapt to a new way of living and managing care that can feel isolating and overwhelming.

UCI MIND, too, has had to undertake significant adjustments, but our mission to end Alzheimer's disease and to serve as a resource of expertise and support to our community continues. During the pandemic, we have had to temporarily change our approach to research. Most of our laboratory scientists are working from home, analyzing existing data and writing papers while experiments are temporarily on hold. Some research personnel have special permission to visit the laboratory (practicing social distancing and minimizing time spent on campus) to tend to animal colonies, feed cell cultures, and perform other essential practices to minimize damage to research initiatives.

continued on page 3

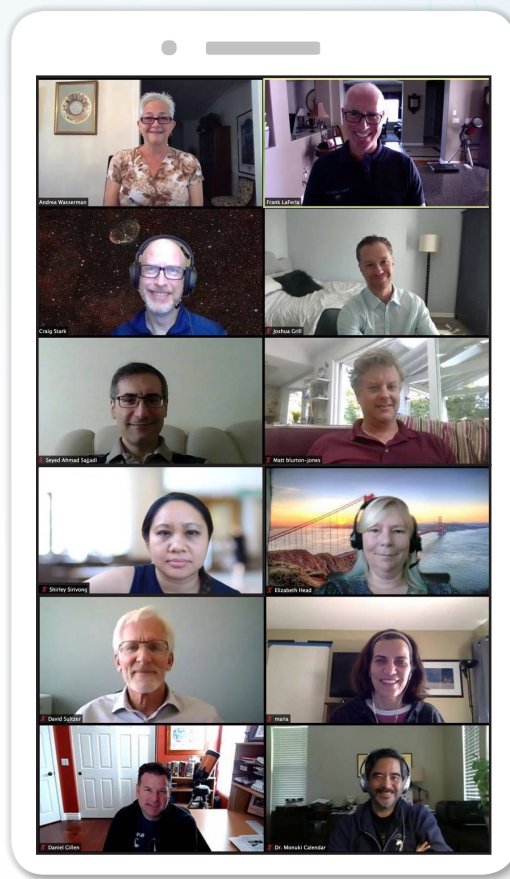
IN THIS ISSUE

Adapting to change in the wake of COVID-19

Researchers and advocates share messages of hope

Alzheimer's fundraising during COVID-19

Conducting clinical trials during a pandemic



UCI MIND Alzheimer's Disease Research Center leaders collaborate via Zoom

MESSAGE FROM THE DIRECTOR

Dear Friends of UCI MIND,

Since writing my last message for our Winter 2020 issue, we have all had our worlds turned upside down by COVID-19. At UCI MIND, we have faced challenges and have had to temporarily adapt our research programs (pp. 1, 3). But, I know these challenges pale in comparison to those faced by members of our community. I'm especially concerned about the additional challenges faced by caregivers of people living with dementia, as well as the social isolation physical distancing can bring to older people who are living alone.

We are eager to help any way we are able. We are regularly posting messages from our team (p. 4) and COVID-19 resources on our Blog and social media accounts (p. 8). Our YouTube channel offers hours of educational content, and we continue our monthly Q&A sessions on Facebook Live with UCI MIND researchers (p. 6-7).



For the latest news, stories, and resources, visit www.mind.uci.edu/blog

We will be offering more opportunities for online research participation through our UCI C2C Registry – anyone 18 and older can sign up and it only takes 20 minutes to enroll online (c2c.uci.edu).

We are eager to hear your ideas of how we might better serve you, our community of volunteers, advocates, patients and caregivers. Please email us at research@mind.uci.edu.

Most importantly, stay safe. Follow the CDC and state and local guidelines. Do your part to help address the COVID-19 crisis. We will get through this together, even if we cannot be *together*.



Joshua D. Grill, PhD
Director, UCI MIND

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Radiation Oncology

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Daniel Gillen, PhD, Chair
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No gatherings

Telecommute



Stay at least
6 feet apart

Arrange virtual
meetings



In human research, we have transitioned some observational studies to telephonic data collection. Others, like our Alzheimer's Disease Research Center (ADRC) "Longitudinal Study," which involves annual study visits with 400 participants at UCI MIND, are on hold. Having participants come to UCI for visits would force them to violate safer-at-home practices and put them at risk. This is true for our Down syndrome and 90+ Studies as well. ADRC leaders have engaged in robust conversations around best practices to continue these studies while maintaining data integrity and keeping participants and research staff safe. In all cases, we are staying in close communication with our participants and look forward to meeting with them again soon to continue these critical studies.

For clinical trials, studies that involve an intervention such as an investigational drug, the risk-benefit ratio is more complex. An additional consideration is to ensure participants are safe while taking investigational medications. In-person visits continue in many trials. In close partnership with the UCI School of Medicine and the UCI Institute for Clinical and Translational Science, we have taken immediate steps to minimize the risk of virus transmission for trial staff and participants by consolidating activities and carefully scheduling to minimize participants' interactions during visits.

So, we are doing everything we can to ensure our critical research continues, while prioritizing the safety of our participants and our researchers. We have also increased our website and social media presence by posting daily resources and messages from our team to support our community during these challenging times.

We do not know when things will be back to "normal," but we do know that we will get through this together.



UCI MIND clinical research faculty and staff at Hewitt Hall (above) and screen shots from home (below)

We are facing an unprecedented public health crisis, but when we get past it (and we will), the crisis of Alzheimer's disease and related dementias will remain.



Researchers & advocates share messages of hope

The COVID-19 pandemic has impacted all of us on personal and professional levels. Here, we compiled sentiments from blogs posted by UCI MIND researchers and advocates during quarantine:

“

Coronavirus will pass. We will all get through this together. The research at UCI MIND will continue and bright minds will figure out solutions. In the meantime, treat your loved one with Alzheimer's as if it's just another lovely day. Then for them, hopefully it will be.

”



UCI MIND LEADERSHIP COUNCIL MEMBER,
FORMER CAREGIVER
Virginia Naeve

“

I believe as we go through maybe the scariest time in our lives, there will be value that comes from it. We will be faced with having to make another transition. One that will make us stronger, more open to new approaches and hopefully able to work together in harmony...again.

”



UCI MIND LEADERSHIP COUNCIL
MEMBER, FORMER CAREGIVER
Steve O'Leary

“

The ways in which the COVID-19 pandemic has changed our lives are so profound that I fully expect us to, at least in our own heads, divide our life events to pre- and post-pandemic. I cannot think of a similar example in my life that affected every single aspect of my daily living....Negatives aside, it has also been an eye-opening experience that has made me eternally grateful for the things we take for granted in our busy and hectic lives.

”

UCI MIND FACULTY MEMBER,
NEUROLOGIST
Ahmad Sajjadi, MD, PhD



“

As an advocate for UCI MIND, I really miss attending meetings and events and cannot wait until this is over to start speaking again to the community about the impact of Alzheimer's disease on families, how you can lower your chances of getting this horrible disease, and what UCI MIND is doing for the SoCal community. In times like these, families impacted by Alzheimer's disease must all come together to support one another. We are very lucky to have the UCI MIND community to communicate and share in this experience together.

”



UCI MIND LEADERSHIP COUNCIL
MEMBER, FORMER CAREGIVER
Bill Edwards

“

It's really important at this time to be kind to each other, to check in with the people you love, stay healthy, wash your hands, and we'll get through this together.

”



UCI MIND POSTDOCTORAL SCHOLAR
Nicole Schartz, PhD

Alzheimer's fundraising during COVID-19

COVID-19 has impacted every facet of life, including fundraising for the fight against Alzheimer's disease and related dementias (ADRD). The UCI MIND donor community includes caregivers dealing with even more daily stress, business owners who are struggling to pay their employees, parents who have become home school teachers, and philanthropists who have redirected their giving during this unprecedented time to help those most vulnerable and on the front lines of caring for people with COVID-19.

Though the recovery from COVID-19 will take time, our mission to rid the world of ADRD through cutting-edge research remains a priority. We know many of you are answering the call to support your

communities in crisis, and supporting UCI MIND may be temporarily delayed. We understand and endorse these decisions. We look forward to a time when the UCI MIND community will once again gather together and we can redouble our efforts to accelerate research through philanthropy. As with COVID-19, Alzheimer's disease will be stopped through global, collective action.



Danny Harper
Senior Director of Development

**Joe Gonzalez, Harriet Harris,
Marla Noel, Jennifer Simpson,
Keith Swayne, Jonathan Varenchik,
& Burton Young**
*UCI MIND Leadership Council
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Thank you to our donors



To make a gift, call 949.824.3793
or visit www.mind.uci.edu/donate

Gifts of \$100,000+ (since Apr. 2019)

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Henry L. Guenther Foundation
Willard V. Harris, Jr. &
Mrs. Harriet A. Harris
Mr. Robert A. Kleist
Living Legacy Foundation
Keith Swayne
In memory of Elsa C. Watson,
by the Ray and Elsa Watson
Charitable Trust
Women's Alzheimer's Movement

Gifts of \$50,000+ (since Apr. 2019)

Anonymous*
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The Leandro P. Rizzuto Foundation

Gifts of \$5,000+ (since Apr. 2019)

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Mrs. Sheila Finnegan Harris
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Patricia Ruth O'Leary
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Mrs. Karen Rockel Speros

* Indicates multiple donors

Conducting clinical trials during a pandemic



Q&A with UCI MIND Faculty Member, Daniel L. Gillen, PhD, Professor and Chair of Statistics, Professor of Public Health and Epidemiology at UCI. Dr. Gillen serves on national and international Data Safety and Monitoring Boards evaluating the safety of ongoing clinical trials, and he has participated on multiple FDA advisory panels that are instrumental in deciding which drugs get approved and which do not.

What exactly is a clinical trial?

Gillen: A clinical trial, broadly speaking, is a designed experiment to test and assess an intervention in a human population. We generally think of trials in terms of the phases and a scientific goal. In the drug development process, we have four primary phases of clinical trials. Phase I trials are generally smaller studies that look at a biological component, also known as dosing trials. The goal of a Phase I study is to determine safety, or the maximum tolerable dose in individuals. Phase II studies are proof-of-concept studies that look at the likelihood of efficacy on your outcomes of interest. For instance, if you're

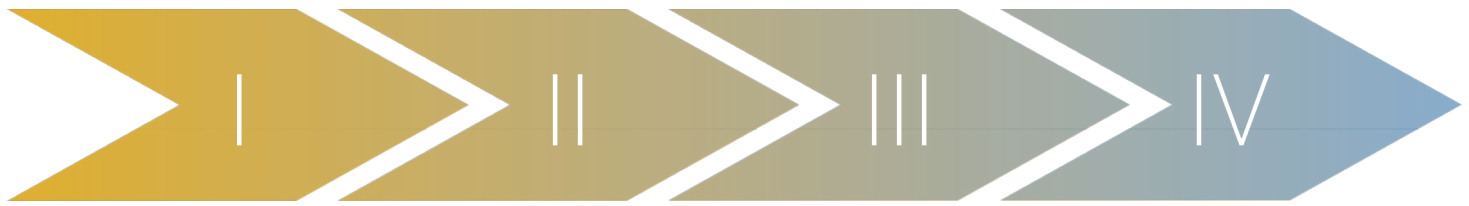
conducting an Alzheimer's disease (AD) study, are there hints that this drug is lowering amyloid-beta or tau levels in a patient? The goal is to move to Phase III studies, which is what most people hear about in the news. Phase III studies are the penultimate step in the trial process before regulatory approval. They are much larger in size and aim to prove or disregard a new treatment. Phase IV is an active surveillance study which looks at longer-term outcomes, such as AD progression, and safety effects once the drugs are prescribed and used by the community.

Why are clinical trials essential to find new treatments for AD and other health conditions?

Gillen: It comes down to ethics and efficiency. If you didn't know the safety and correct dosing level of a drug, you wouldn't want to experiment on a large number of individuals in a Phase III study; that is the rationale for earlier phase studies. Phase II studies act as screening studies and save time, resources, and number of participants needed. In Phase III, you need to have enough precision to be able to say with confidence that a drug works. My job is to increase the number of effective therapies in the population, and well-designed Phase III studies allow us to do that. Phase IV studies are an ethical consideration, because you wouldn't want to use urgently-needed drugs, like COVID-19 vaccines and AD interventions, if they don't work or are harmful. We do want to get these to the population and begin looking at things long-term. There's a very good rationale for all four phases that we have.

Are clinical trials still necessary during an urgent public health crisis like COVID-19?

Gillen: Sound clinical trials are absolutely critical and necessary, even during a crisis. It is imperative we develop therapies that are safe and known to work. There are individuals who say we should rush to put therapies out based on anecdotal evidence or case studies. That's not a good idea. At best, if an individual is taking something that doesn't actually



In the drug development process, there are four primary phases of clinical trials to ensure safety and efficacy of new drugs.

work, it could give false security and would likely preclude them from taking something else that could work. At worst, you're doing more harm than good. To avoid that, we need well-designed trials that look for imbalances and confounding factors that could alter the associations you may see. We do need clinical trials and strong evidence; however, we may not need all phases in some studies. The drug *remdesivir*, for instance, blocks mutations for Ebola. We fast-tracked a Phase III trial to see if it lowers recovery time for COVID-19, and its emergency use was recently authorized. It is one of the quickest trials done in history. We will continually vet our data, but we don't want to avoid the principles of safe and efficacious studies.

In the news, we have seen a lot of work toward a vaccine for COVID-19. How long will it take to develop, test, and approve a new vaccine like this?

Gillen: The true milestone would be a vaccine. The UCI research and development team is considering many target candidates. Developing antibodies for these targets could allow us to block the virus. We don't have the target yet, but these studies will be fast-tracked, and by early 2021 we could optimistically foresee a vaccine. In order to make a vaccine useful, we would need mass-production while the study is ongoing. It'll take time, and there is likely to be a second wave; but in the meantime, we've been bending the curve with important public health practices like social distancing.

During the pandemic, with working remotely and safer-at-home orders, what happens to AD clinical trials?

Gillen: Opinions range from completely shutting down operations to continuing research in certain situations. In accordance with FDA guidance, we want to ensure participant welfare and safety, no matter what. Not all trials are the same. Late-stage therapies may need to continue, while more benign studies could modify certain protocols. At UCI MIND, we're doing our best to retain individuals in studies, follow their outcomes of interest, and adhere as closely to protocol as possible. Examples of modifications include moving in-person visits to phone or online. Necessary in-person visits may take place in alternate locations, such as a participant's home. The age range of participants in AD research often places them at highest-risk for COVID-19 associated co-morbidities. We are acutely aware of this as we continue to develop novel and more effective therapies for AD and related disorders while protecting participants.

Do you think this pandemic will set us back in discovering new and improved treatments for AD and related disorders?

Gillen: In the long run, I don't think the pandemic will have a significant impact on the development of novel treatments for AD. There will be a short-term impact, as we deviate somewhat from protocols, pause some recruitment efforts, and put nonessential in-person visits on hold. However, I am very optimistic that we will continue to make progress, and I see this as a bump on the road in the longer journey to develop novel and effective therapies.



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Research Participation

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Connect with us
on social media!

OC COVID-19 RESOURCES

ASSIST Program for Isolated Seniors

UC Irvine | 714.497.0315

Virtual Caregiver Support Groups

Alzheimer's Association | 800.272.3900
Alzheimer's OC | 844.435.7259

Food, Housing, Financial Support

211OC | Call 211 or Text Zip Code to 898-211

In Home Supportive Services (IHSS) Hotline

OC Social Services Agency | 714.825.3000 (Dial 4)

Mental Health Support

NAMI Warm Line | 877.910.9276
New Hope Crisis Hotline | 714.639.4673



For more resources, visit
www.mind.uci.edu/blog



Upcoming events

31st Annual SoCal Alzheimer's Research Conference

Thursday, September 10, 2020

11th Annual A December to Remember Gala

Saturday, December 5, 2020

2020 Facebook LIVE Q&A Series

Guest experts from UCI MIND

First Friday of every month | 11:00 - 11:30 am PST



Learn more about our upcoming
events at www.mind.uci.edu/calendar