

# MIND Matters

WINTER 2021

## SPECIAL FEATURE

## Light at the end of the tunnel

Though it will take time, the end of the pandemic is in sight with two FDA-approved COVID-19 vaccinations being distributed daily. As of January 11, Orange County has approved vaccinating prioritized groups, including people aged 65+.

The County opened its first regional COVID-19 Super POD (Point-of-Dispensing) site to residents at Disneyland on January 13. A second site at Soka University started mass vaccinations on January 23. Vaccines are available at these sites by appointment only through [othena.com](https://www.othena.com). Once registered, individuals will be notified via app or by email when appointments become available and then can sign up for times at either location.

Additionally, UCI Health offers vaccinations at the UCI Bren Events Center on campus for UCI Health patients by appointment only, following the same County guidelines for prioritized groups. Vaccine appointments can be made directly through UCI Health's MyChart or by going to [vaccine.ucihealth.org](https://vaccine.ucihealth.org).

 For more FAQs about the vaccines, visit [ucihealth.org/covid-19/covid-vaccine-faq](https://ucihealth.org/covid-19/covid-vaccine-faq)

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### Is it safe to get vaccinated?

Neither of the authorized COVID-19 vaccines, nor those currently in U.S. clinical trials, contains the live virus that causes COVID-19. This means the vaccine cannot make you sick with COVID-19. Vaccines teach our immune systems to recognize and fight the virus, a process that can cause symptoms such as fever, headache, chills, aches. These symptoms are normal and are a sign that the body is building protection against COVID-19.

Both COVID-19 vaccines were granted emergency approval because they met high U.S. safety and efficacy standards. Large clinical trials, involving tens of thousands of people who were randomly assigned to active vaccine or placebo, demonstrated that each of the two available treatments are >90% effective in preventing COVID-19. And importantly, individuals ranging in age, race, and ethnicity were enrolled in both vaccine trials and demonstrated that the vaccines work equally well across all subgroups included in the studies. Additional clinical trial results, including those for single-dose vaccines, have also been promising and could accelerate the timeline to ending the pandemic.

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Happy New Year, Friends of UCI MIND!

For many of us, a New Year brings the promise of fresh starts and new beginnings. In 2021, it also means a welcomed good-bye to a very long 2020. Despite the challenges that 2020 brought, it also brought progress that must now continue in 2021. This includes progress in social justice, progress in fighting the COVID-19 pandemic, and progress in research to rid the world of Alzheimer’s disease and related dementias. UCI MIND is committed to contributing to further progress in each of these areas.

Though the COVID-19 pandemic has complicated all aspects of life, there is light at the end of the tunnel (p. 1, 3). As we emerge from a troubling year, we are focused squarely on returning all studies to their full activity levels as soon as we can safely do so. We will also not lose sight of the social movements that accelerated and reached new heights in 2020. UCI MIND is supportive of the Black Lives Matter movement and inclusiveness and diversity in

research. UCI MIND has long been a national hub for research in people with Down syndrome (p. 4), who are understudied in many areas of research. Our efforts also focus on including people of all races, ethnicities, and socioeconomic statuses in research (p. 7). Many ongoing efforts aim to increase our reach and inclusivity, such as the launch of UCI MINDcast (p. 6).

Now, it is time to turn the page from 2020 and look optimistically toward our future. On the backs of research advances, we hope this future will bring an end to the COVID-19 pandemic. On the backs of research advances, we hope this future will also bring an end to Alzheimer’s disease and related dementias.



*Joshua D. Grill*

**Joshua D. Grill, PhD**  
Director, UCI MIND

## Faculty members

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Alan Goldin, MD, PhD  
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Steven Schreiber, MD  
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Michael Leon, PhD  
Craig Stark, PhD  
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### Radiation Oncology

Charles Limoli, PhD

### Statistics

Daniel Gillen, PhD, Chair  
Bin Nan, PhD

## **I am eligible to get vaccinated but cannot get an appointment. What should I do?**

While there is limited supply of COVID-19 vaccines currently, the supply will increase over time. Current vaccination appointments are contingent on vaccine availability and administration capacity, and efforts are underway to increase both. While many older adults are anxious and eager to get the COVID-19 vaccines, we suggest considering the following:

- Register at [othena.com](https://othena.com) to be notified when an appointment slot becomes available. As the supply increases and additional Super POD sites open, more appointment slots will be made available. You only need to register once to be notified via app or email when it is time to schedule.
- For UCI Health patients, regularly check UCI Health's MyChart or [vaccine.ucihealth.org](https://vaccine.ucihealth.org) to see if appointments at the UCI Bren Events Center become available. There is no waiting list to join at this time.
- Discuss vaccination with your primary care provider or health plan to determine if there are other options that may be available to you.
- Veterans can contact VA providers to see if vaccination appointments are available.

Whether a person has been vaccinated or not, we strongly encourage everyone to continue COVID-19 prevention practices, including mask wearing, physical distancing, and frequent hand washing.

## **Have UCI MIND doctors and staff received vaccinations?**

As part of the County's efforts to vaccinate healthcare workers, all clinical research staff who are involved with UCI MIND study research visits have completed their COVID vaccinations or will soon.

Researchers who are not directly interacting with study participants in-person or who are not at direct risk of exposure in their day-to-day workplace interactions will await guidance from the University as the County provides timeframes for additional tiers to be included in vaccination efforts.

Whether a person has been vaccinated or not, we strongly encourage everyone to continue COVID-19 prevention practices, including mask wearing, physical distancing, and frequent hand washing.

## **Is it safe to attend in-person research visits at UCI MIND?**

Participant safety is our highest priority. We have limited in-person study visits for clinical trials at this time. With increased vaccinations and reduced hospitalizations and infections in the County, we hope to restart additional studies as soon as it is safe to do so.

We have taken several steps, in addition to our standard rigorous infection control measures, to ensure our facilities remain safe for those coming for study visits:

- Daily Health screening for COVID-19 symptoms, including survey of recent travel history or potential exposures, as well as temperature checks for all staff and individuals coming for in-person activities.
- All staff, study participants, and study partners (as well as any visitors) are required to always remain masked. Those who do not have a face mask are provided one.
- Exam and testing rooms are fully cleaned and disinfected before and after each use.
- Schedules have been adjusted to limit the number of individuals who are seen at any time. Physical distancing is always maintained, and staff are diligent to ensure participants are settled into a private room to reduce unintended interactions.
- All common areas are regularly cleaned with special attention to high touch surfaces.

As clinical researchers and participants continue to complete vaccinations, the UCI MIND team will assess the timing and logistics to expand in-person study visits. We are committed to our research mission and resuming normal in-person study activities as quickly and as safely as possible.



# A letter from the McElroy family:

## *Remembering Matt, a pioneer in Down syndrome research*

Our brother, Matthew "Matt" McElroy, was introduced to the UCI Down Syndrome Program in 1997 when he was 35 years old. Our Mother heard about the program, led by Dr. Ira Lott, through her community of Down syndrome parents.

Just a year earlier, our Dad had passed away suddenly, and it seemed to hit Matt harder than most. As time went on, we noticed symptoms of depression and distinct changes in his personality. So, we made an appointment with Dr. Lott, and from that point until he passed away at age 58 on February 1, 2020, UCI had a critical relationship with Matt and our family.

Matt was a very social person and loved the attention he received from the research staff. He was treated with great care and dignity, and we developed trust – especially with the Program Manager, Eric Doran. Eric never let us down and was critical to our understanding of what Matt was going through and what we could expect as his disease progressed. Initially, the Down Syndrome Program was a way for us to find answers about Matt's behavior changes. But we also learned about the outsized impact of dementia in the Down syndrome population.

While Matt could communicate with us in his unique way, he was largely non-verbal in a classic sense. As his dementia progressed, he withdrew more and more and his interest in communicating suffered. When Matt could no longer manage office visits, the doctors and staff came to our family home for regular physical and behavioral checkups. The team was always patient, kind and available by phone for questions and advice. They functioned as friends and guides on this sad journey until the very end.

Without the Down Syndrome Program, there are points where we would have felt lost. The staff came to care about Matt as a person first, not just a research subject – a kindness that extended to our whole family.



*McElroy family*

When Matt passed away, our family made the collective decision to donate his brain. The years Matt had dedicated to the program and the research that might help other families facing the same journey made our decision easy.

Matt was a gift to our world, and we know that this was a way he could keep on giving. He was a pioneer his whole life – as a personality, an athlete, a brother, a son and a community member. The Down Syndrome Program allowed Matt to continue to make a difference in the world. Matt always made a difference.

The UCI Down Syndrome Program was a rich and enormously helpful experience for the McElroy family, and we are both proud and very grateful to have been a part of it with our brother.

*Pat McElroy      Eileen McElroy      Kevin McElroy  
John McElroy      Dan McElroy*

Matt starred in a 1980-1981 Special Olympics Commercial with Jim Chones, forward on the World Champion Lakers. View the clip here: <https://youtu.be/H2neG32O-dg>

# Virtual Gala warms hearts, opens minds, drives donations both on & offline

UCI MIND's *A December to Remember* Gala on December 5, 2020, exceeded expectations in every way. The event took place virtually for the very first time amid the COVID-19 pandemic, reaching over 850 viewers. Motivated by personal stories, world-class entertainers, and enticing auction items, donors gave over \$300,000 toward UCI MIND's vision to rid the world of Alzheimer's disease and related dementias.

"Not only did viewers offer UCI MIND an overwhelming amount of support through their donations, they also offered rave reviews of the broadcast," said Chair of the Gala Committee, Virginia Naeve. "It was an honor to work with such dedicated committee members who helped produce a powerful virtual event benefiting such an important cause."

The online broadcast, co-hosted by director Joshua Grill and auctioneer Zack Krone, featured performances from Justin Willman, creator of the hit Netflix series *Magic for Humans*, and Ashley Campbell, singer-songwriter and daughter of the late Glen Campbell. Both performers shared the impact of Alzheimer's disease on their own lives, making their segments as poignant and powerful as they were entertaining.

Though the Gala has passed, it can still be viewed on YouTube, and donations can be made online or by using the enclosed envelope.



## Thank you to our donors

 To make a gift, call 949.824.3793 or visit [www.mind.uci.edu/donate](http://www.mind.uci.edu/donate)

### Gifts of \$100,000+ (Dec. '19-'20)

Brethren Community Foundation  
Henry L. Guenther Foundation  
Willard V. Harris, Jr. & Harriet A. Harris  
In memory of Patricia Ruth O'Leary  
Orange County Community Foundation  
Keith Swayne

### Gifts of \$50,000+ (Dec. '19-'20)

Anonymous  
Mr. Robert A. Kleist  
Women's Alzheimer's Movement

### Gifts of \$5,000+ (Dec. '19-'20)

Anonymous\*  
The William K. Applebee Family Trust 1995  
Ambassador & Mrs. George L. Argyros  
Joan & Don Beall  
Arnold & Mabel Beckman Foundation  
Mary Behrens

\* Indicates multiple donors

### \$5,000+ (continued)

Belmont Village, Aliso Viejo  
Lorna Seema Carlin, M.D.  
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Michael Chang Tennis Classic  
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Harris Taylor Family Foundation  
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### \$5,000+ (continued)

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Rand & Rosemary Sperry

### \$5,000+ (continued)

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Chris & Kathy Taylor  
Warren & Jennifer Taylor  
Dr. David Thomsen & Mrs. Kathryn Kendall  
Burton & Linda Young

### UCI MIND Legacy Society

(Donors who have included UCI MIND in their estate plans)  
Anonymous\*  
Mrs. Shirley Bloom  
Lorna Seema Carlin, M.D.  
William Robert Chase, D.D.S.  
Mr. Bill P. Harris & Mrs. Sheila Finnegan Harris  
Ms. Paula Hunter  
Mrs. Carla Liggett  
Mrs. Carol Murrell  
In memory of Patricia Ruth O'Leary  
Mrs. Carolyn Rorman  
Mrs. Karen Rockel Sperry

# The mind behind UCI MIND's new media hub

Meet Gil Aranowitz, Director of Creative Strategy at *The Best Words Win* in Irvine, a firm that helps clients meet their marketing goals through creative strategies, like storytelling. Gil joined UCI MIND's Leadership Council in 2018 to support marketing efforts led by fellow Council Member, Steve O'Leary. At the time, Gil's wife was struggling to provide remote support for her mother with Alzheimer's disease in Tokyo. And so, Gil's involvement with UCI MIND began as a symbolic way to show support for his family.



*Gil Aranowitz*

When the pandemic hit, UCI MIND was challenged to come up with new creative "virtual" ways to engage the local community. Tapping into Gil's expertise in marketing strategy and creative development, the idea for "UCI MINDcast" was born.

UCI MINDcast is UCI MIND's new video and podcast library with up-to-date content on the latest in Alzheimer's and dementia research, education, and care. Content categories include Ask the Doc, Truth or Myth, Accelerating Discovery, Be the Solution, Meet the Team, and Spotlight on Care, a new podcast for caregivers hosted by Leadership Council Members, Steve O'Leary and Virginia Naeve.

## How did you come up with the idea for UCI MINDcast?

**Gil:** Steve asked me to start thinking about how UCI MIND

should use video starting in 2021. I like to start with the ideal solution, which was to try to find a way to organize all our video efforts into an efficient, strategic framework. Doing that helped us clearly see the opportunity to start podcasting as well. As we mapped out the framework and plan, I tapped into the right side of my brain and came up with the name UCI MINDcast to brand it. It just made sense!

## How do you hope UCI MINDcast will help our community?

**Gil:** I hope UCI MINDcast, as an initiative and organizing principle, makes it easier for people to find the information they need, whether it be caregiving tips, research updates, or prospective community members wanting to learn more about UCI MIND.

## What motivates you to volunteer with UCI MIND?

**Gil:** The great work being done by UCI MIND and the passion everyone has for the mission. Enthusiasm is contagious. Also, Steve has been great at raising the bar for what we can do from a marketing standpoint. I love the challenge and knowing that the next year will be better than the last. It's humbling to be able to use my creativity to support an organization like UCI MIND. Getting back to why I got involved in the first place, I'm grateful for the opportunity to help.



*Virginia Naeve and Steve O'Leary recording the first episode of Spotlight on Care, a caregiver-focused podcast*



## Engaging Korean Americans in dementia research & education

In recent years, UCI MIND has developed a community partnership with Somang Society, a Cypress-based non-profit organization with the mission of promoting “Well-Aging, Well-Being and Well-Dying” for Korean American (KA) older adults and their caregivers in Southern California.

For the past fourteen years, Somang Society has provided numerous educational seminars in Korean and English on aging and end-of-life issues for KA older adults with limited English proficiency. Programs include Somang Dementia Forum, Somang End-of-Life Forum, Somang Care Class for KA older adults with early-stage dementia, Somang Family Caregiver Support Groups, and YouTube Dementia Education Series with UCI MIND researchers. Somang Society has also been at the forefront of education on the importance of organ donation for medical research. As a result, over 1,798 KA older adults have registered for the UCI Willed Body Program through Somang Society since 2008.

Somang Society recognizes that clinical research participation from the Asian American community including Korean Americans is extremely limited, yet critical to improve understanding of health and diseases, such as Alzheimer’s, in diverse populations. So, in partnership with UCI MIND, Somang Society aims to dispel the negative stigma about medical research via culturally competent education and to facilitate KA older adults’ participation in federally funded clinical research such as the UCI Consent-to-Contact Registry ([c2c.uci.edu](https://c2c.uci.edu)) and the Collaborative Approach for Asian Americans & Pacific Islanders Research and Education (CARE) ([careregistry.ucsf.edu](https://careregistry.ucsf.edu)), both of which are available in Korean, Mandarin, and Vietnamese.

To support these efforts, Mrs. Boon Ja Yoo, President of Somang Society joined the UCI MIND Leadership Council as the very first KA member. And Hye-Won (Grace) Shin, PhD, serves as Director of Asian



(from left) Hye-Won Shin, PhD and Boon Ja Yoo

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American Community Outreach for UCI MIND. Dr. Shin’s role is to establish partnerships with various Asian American community organizations, to provide scientific evidence-based community education programs and to conduct research studies in both English and Korean. In parallel, Dr. Shin serves as a Community Advisory Board member for CARE by representing Somang Society.

UCI MIND and Somang Society are hopeful that through this community partnership, we can facilitate diversity and inclusion in medical research and improve understanding of Alzheimer’s disease and related dementias among Asian Americans.



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**National Institute on Aging**  
Designated  
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Research Center**



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### Research Participation

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**Connect with us  
on social media!**

## OC COVID-19 RESOURCES

### Facility for COVID-19+ Dementia Patients

Alzheimer's OC | covid@alzoc.org

### 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



### Upcoming events

#### Ask the Doc Video Series

#### *Guest Experts from UCI MIND*

New Episodes Monthly  
UCI MINDcast | mind.uci.edu/mindcast

#### Spotlight on Care Podcast Series

#### *Steve O'Leary, Virginia Naeve, & Guests*

New Episodes Monthly  
UCI MINDcast | mind.uci.edu/mindcast

#### 32<sup>nd</sup> Annual SoCal Alzheimer's Disease Research Conference

Friday, September 10, 2021  
Save the Date!



**Past education sessions are archived on  
UCI MINDcast and youtube.com/ucimind**