



# MoND Matters

A quarterly publication of UCI MIND

Winter 2018

## DESPITE "FLOPS," CLINICAL TRIALS BRING HOPE

Negative headlines about Alzheimer's disease (AD) like "failure" and "flop" litter the media. It's true – developing improved therapies for this complex brain disorder is extremely challenging and many



once promising candidate treatments have ultimately failed to pass muster in clinical trials. Developing AD treatments is so difficult that one industry giant, Pfizer, announced in January a plan to end research efforts into AD and Parkinson's.

Yet, it is without a doubt the most optimistic time in the history of AD research. Many pharmaceutical companies have increased their investment in AD, recognizing the importance of the disease and the size of the market. Further, many of the challenges that are hypothesized to have played a role in recent failures are being addressed:

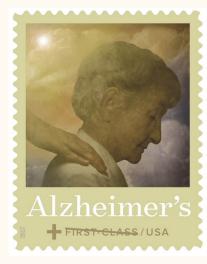
- 1. Until recently, we had no treatments that specifically targeted the underlying biology of AD. Now, at UCI, we are testing treatments that directly target the amyloid plaques and neurofibrillary tangles that contribute to the disease. We are even testing combinations of treatments.
- 2. Many in the field believe early intervention will

be necessary to successfully slow or halt AD. We are now testing this hypothesis with promising treatments at several disease stages, including in people with no memory problems.

3. Clinical trials take a very long time, in part because of the challenges in recruiting participants. At UCI we started the Consent-to-Contact Registry (C2C) to help match community members who want to participate in research with studies for which they may qualify (c2c.uci.edu). In addition, we participate in important academic networks such as the AD Clinical Trial Consortium, which was recently awarded \$70 million by the National Institute on Aging to perform cutting edge clinical trials over the next five years.

Despite challenges, UCI MIND will remain at the forefront of developing improved treatments and prevention for AD. Every clinical trial, whether the drug is effective or not, brings answers to researchers and guides our agenda. To learn more about what we have learned from past clinical trials, promising interventions currently under study, and where the field is headed, save the date for the 29th Annual Southern California Alzheimer's Disease Research Conference hosted by UCI MIND and Alzheimer's Orange County on September 21, 2018 at the Irvine Marriott Hotel.

## USPS ISSUES STAMP TO SUPPORT ALZHEIMER'S DISEASE RESEARCH



In November 2017, The U.S. Postal Service issued a 65-cent First-Class stamp to help raise awareness and funds for Alzheimer's disease research. The stamp, designed by Matt Mahurin and Ethel Kessler, depicts the profile of an older woman with a caring hand on her shoulder, the sun behind her and clouds ahead of her. Net proceeds from the stamp will be distributed to the U.S. Department of Health and Human Services to support Alzheimer's disease research. USPS selects causes deemed to be in our country's immediate interest, stating Alzheimer's disease "poses enormous challenges for family members and caregivers. Today, Americans are increasingly committed to finding ways to prevent, treat, and someday stop this heartbreaking disease." Stamps can be purchased at your local post office or online at:

https://store.usps.com/store/product/buy-stamps/alzheimers-S\_564204

## FROM THE CO-DIRECTORS



As in previous issues of *MIND Matters*, we are pleased to write to you with optimism and reports of progress at UCI MIND. We continue to see our investigators make critical discoveries and test promising new treatments (page 1). Alzheimer's disease (AD) and other brain disorders represent major public health crises and will require collaborative efforts by researchers, industry, and the community at large if we are to achieve our mission.

Perhaps for the first time, international leaders are taking center stage as advocates for AD research. This includes Bill Gates who recently committed \$100 million of his personal finances to research. And Maria Shriver has not only pointed a spotlight on AD through her role at NBC's Today show, she has partnered with UCI MIND to fund new lines of research at our Institute (page 3).

While these public figures play a critical role in national and international advocacy, UCI MIND is fortunate to interact daily with local advocates who donate their time and resources to support our research efforts. In this issue of *MIND Matters*, we recognize the contributions of two remarkable volunteers. Michael Todd is a UCI alum (Zot Zot!) who has contributed his talents to help launch a new initiative with the UCI Alumni Association (page 3). And with heavy hearts, we say goodbye to Michael Diaz Portillo (below). Michael and his mother Frances Saldana have been tireless advocates for Huntington's disease research at UCI MIND. We extend our personal gratitude to these remarkable champions and families.

### IN MEMORY OF MICHAEL DIAZ PORTILLO

On September 24, 2017, Michael Diaz Portillo passed away after a 17-year battle with Huntington's disease (HD). Michael was the son of Hector Portillo and Frances Saldana, the founder of UCI MIND's partner organization, HD-CARE, which aims to advance HD research and clinical care at UCI.



**Michael Diaz Portillo** 

Michael was one of three children who inherited HD from their father, all of whom have passed away from the disease. Michael's lifelong dream was to establish his own restaurant, and he worked hard toward achieving that goal, making several trips to Paris to learn French cuisine. Later he worked for commercial fisheries out of Alaska and hoped to soon have enough funds to start his restaurant. Knowing the clock was ticking and there was still no treatment for HD, Michael worked harder and faster, but symptoms of the fatal disease began to surface. He finally decided to undergo genetic testing and learned he was positive for the disease.

As fast and furious as Michael worked, he was never able to realize his dreams of owning a restaurant, getting married, and having children. He never gave up hope for a treatment and participated in many fundraisers to support HD research. With no cure or

treatment, the disease progressed until he was totally disabled. He entered his first care home at the age of 34, where he spent the next 10 years. His legacy is remembered at UCI MIND's HD Exhibit, available for anyone to visit.

If you would like to make a gift in memory of Michael, please click **here.** 



## A DECEMBER TO REMEMBER GALA RAISES \$280,000

UCI MIND celebrated its annual A December to Remember gala at the Balboa Bay Resort on December 2, 2017. The event, chaired by Robert and Virginia Naeve, raised over \$280,000 to support research at UCI MIND. Research participant, philanthropist, and caregiver, Suzy Melin, was honored for her dedication to Alzheimer's disease research with the 2017 Community Leadership Award. And influential Alzheimer's advocate, Maria Shriver, was honored for shining a spotlight on Alzheimer's disease through the HBO documentaries "The Memory Tapes," and more recently, spearheading a non-profit organization committed to supporting research, The Women's Alzheimer's Movement.

Ms. Shriver, during her acceptance of the UCI MIND award, announced a new partnership with UCI MIND to support women-focused research. The initiative will award pilot grants to UCI researchers with high caliber scientific proposals to investigate the role of sex and gender disparities in Alzheimer's disease.

Overall, the annual gala again proved to be a great success in raising funds for Alzheimer's disease research and building relationships among our community's leaders in the fight toward improved understanding, diagnosis, and treatment.

We hope you will join us next year for this special evening on **December 1, 2018**. For more information, please contact Virginia and Robert Naeve Linda Scheck at Ischeck@uci.edu or 949.824.3251.

#### 2017 GALA SPONSORS

The Beaumont Family, in Honor of Dr. Jacqueline DuPont The Covington Elite OC Productions HCP. Inc. Susan and Frank Kavanauah Robert and Barbara Kleist The Melin Family Meridian Senior Living Monster Loans Robert and Virginia Naeve, in Memory of Helen Simpson Regency Palms Senior Living Silverado Sperry Equities and Sperry Commercial Swayne / O'Leary Phyllis and Cal Wallace Wham-O







**Honoree Maria Shriver** with Co-Directors Drs. Joshua Grill (left) and Frank LaFerla (right)



**Michael Todd** 

### **VOLUNTEER HIGHLIGHT: MICHAEL TODD**

Michael Todd (UCI '73), with his extensive background in digital marketing and website creation, was introduced to UCI MIND by Steve O'Leary (see Fall 2017 MIND Matters, page 4). Michael was asked to help develop a first-of-its-kind alumni outreach program, a partnership between UCI MIND and the UCI Alumni Association called Anteater's Against Alzheimer's (AAA, aaa.uci.edu). AAA is a Movement for UCI alumni, family, and friends to join together in the fight against Alzheimer's disease by supporting research at UCI MIND.

For AAA to successfully launch, a modern, aesthetically appealing, and well-functioning website needed to be developed. Michael's contributions were both numerous and critical to the launch of the Movement. He took the lead in developing the approach. He

recommended the use of videos to increase engagement and better tell the story. He worked weekends and evenings to draft content, review website structure and design, proof and edit all content created, test the site's functionality, and finally, check the mechanics of donation by making the first gift.

Michael's contributions have been exemplary. But what makes his contributions even more remarkable, though he never mentioned it to UCI MIND at the time, is that all the while he has been fighting his own personal battle against cancer. UCI MIND is grateful to work with altruistic, generous volunteers like Michael Todd. Together, we are advancing neurodegenerative disease research and making a difference.



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## UPCOMING EDUCATION EVENTS

- Friday, March 9 | 8:00 am-12:00 pm
  Ask the Doc @ Senator Pat Bates' South OC Senior Day in Mission Viejo
  Open Q&A with Drs. Ruth Benca, Aimee Pierce, Malcolm Dick & Michael Yassa
- Thursday, March 22 | 1:30 pm-3:30 pm
  Ask the Doc @ The Susi Q Senior Center in Laguna Beach
  Open Q&A with Drs. Joshua Grill, Aimee Pierce, Malcolm Dick & Lindsay Hohsfield
- Saturday, April 7 | 1:00 pm-3:00 pm
  Ask the Doc for Down Syndrome @ Alzheimer's Orange County in Irvine
  Open Q&A with Drs. Joshua Grill, Ira Lott, Jorge Busciglio & Eric Doran, MS
- Wednesday, May 2 | 6:00 pm-8:00 pm
  Ask the Doc @ Fullerton Public Library
  Open Q&A with Drs. Joshua Grill, Ahmad Sajjadi, Malcolm Dick & Mathew Blurton-Jones
- Thursday, May 17 | 9:30 am-12:00 pm
  Family Education Series @ Irvine Lakeview Senior Center
  Presented by Drs. Malcolm Dick & Cordula Dick-Muehlke

Registration is required. Please visit www.mind.uci.edu/calendar to register or call 949.824.9475.

### WHOSE LIFE WILL YOU CHANGE?

With the new tax law changes going into effect, your charitable gifts can make an impact now more than ever at UCI MIND.

For more information, please call Jenna Garza, Office of Planned Giving at **949.824.5121**.

