

FRIENDS of the MIND

Research
making hope
a reality

Abbeduto honored by American Psychological Association



Leonard Abbeduto, director of the UC Davis MIND Institute and professor in the Department of Psychiatry and Behavioral Sciences, is the recipient of the 2017 Edgar A. Doll Award from the American Psychological Association.

The award honors an individual for his or her substantial contributions to the understanding of intellectual or developmental disabilities throughout their career. Abbeduto's research at UC Davis focuses on the development of language across the lifespan in individuals with neurodevelopmental disorders.

Abbeduto received the award at the association's annual conference on Aug. 3, where he also gave an address.

The award was sponsored by the association's Division 33, a professional organization concerned with research and clinical practice as it applies to the lifespan of individuals with intellectual or developmental disabilities and autism spectrum disorder.

Researchers validate mouse model for autism



A study by researchers at the UC Davis MIND Institute and Boston Children's Hospital has verified that mice can be a valuable research tool to develop new therapies for autism.

Jacqueline Crawley, the Robert E. Chason Endowed Chair in Translational Research at the MIND Institute and co-senior author of the study, reported in the journal *Molecular Autism* that mice without the Shank3B protein model aspects of brain physiology and behavioral symptoms observed in people with autism.

"The standard of care for autism is intensive, early behavioral interventions," Crawley said. "In contrast, there are currently no medical treatments that significantly improve the diagnostic symptoms of autism. We are seeking pharmacological targets that correct the biological abnormalities caused by mutations in risk genes for autism."

Crawley said combining an effective behavioral intervention, such as those offered at the MIND Institute, with an effective drug treatment may confer synergistic benefits to people with autism.

Developed at Duke University, Shank3B knockout mice replicate certain autism symptoms, including repetitive behaviors and abnormal brain electroencephalography (EEG) activity. A significant number of patients with an autism spectrum disorder harbor SHANK3B mutations.

To better understand this model and how it might support the search for new therapeutics, the labs at UC Davis and

Boston Children's Hospital compared two independently bred groups of Shank3B knockout mice and control groups.

UC Davis researchers replicated and extended previously-reported behaviors in Shank3B mice, such as repetitive self-grooming and reduced social interaction.

Led by co-senior author Mustafa Sahin, who directs Boston Children's Translational Neuroscience Center, laboratory researchers assessed brain activity in awake mice using EEG methods.

"In each lab, two independently bred cohorts of Shank3B mice and their wildtype littermate controls were tested," said Crawley. "The behavioral and EEG abnormalities were found to replicate well across the two cohorts in both labs."

Both Crawley and Sahin are principal investigators in the Preclinical Autism Consortium for Therapeutics (PACT). Supported by Autism Speaks, which also funded the study, PACT investigates models that could accelerate new autism therapies.

"We recognize that mice and rats cannot recapitulate the uniquely human symptoms of autism," said Crawley. "However, a positive finding in autism-relevant behaviors and physiology in a mouse model with a mutation in a human risk gene for autism increases confidence in a drug's potential benefit."



New grant aims to improve and broaden schools' practices for children with autism

The UC Davis MIND Institute has received a 3-year, \$1.4 million grant to study how to build a statewide network to improve use of evidence-based practices for students with autism spectrum disorders (ASDs).

The grant, from the Institute of Education Sciences, will provide data that will help determine how state, district and school policies and programs influence access to and effectiveness of teacher training in evidence-based practices. The researchers hope to use the data to help policy makers and administrators make changes that improve teacher training and effectively use evidence-based practices for ASDs and more generally.

Aubyn Stahmer, professor of Psychiatry and Behavioral Sciences and director of community-based treatment research at the MIND Institute, is the study's principal investigator. Jessica Suhrheinrich, of San Diego State University, serves as co-principal investigator. The California Autism Professional Training and Information Network (CAPTAIN), a multi-agency network developed to support the use of evidence-based practices for people affected by ASDs in California, is the community leader guiding the project.

"We know that evidence-based practices are important to address a range of complications of autism spectrum disorders, but these interventions are not consistently or effectively used," Stahmer said. "And while special education programs are required to use evidence-based practices to address students' education goals, there are few implementation methods available to help them meet this requirement. This project has implications for improving care for students with ASDs and for developing a system to scale up effective interventions in schools more generally."

In collaboration with CAPTAIN, researchers will use focus groups, surveys and social network interviews to measure the culture, climate, leadership, communication and readiness of educators to implement evidence-based practices in their schools and districts. Their goal is to create a framework for the development of a statewide system to improve implementation of these practices for students with autism spectrum disorders.

"This project has implications for improving care for students with ASDs and for developing a system to scale up effective interventions in schools more generally."

– Aubyn Stahmer

Cerebrospinal fluid shows promise as **autism biomarker**

Researchers from the UC Davis MIND Institute, University of North Carolina (UNC) and other institutions have found that altered distribution of cerebrospinal fluid (CSF) in high-risk infants can predict whether they will develop autism spectrum disorder (ASD). The study was published in the journal *Biological Psychiatry*.



“Normally, autism is diagnosed when the child is two or three years old and beginning to show behavioral symptoms; there are currently no early biological markers” said David Amaral, director of research at the MIND Institute and a co-senior author on the paper. “That there’s an alteration in the distribution

of cerebrospinal fluid that we can see on MRIs as early as six months, is a major finding.”

Produced by the brain, CSF was once cast as a neural shock absorber, keeping the brain from bumping up against the skull. More recent findings have shown that CSF can influence neuronal migration and other mechanisms associated with brain development, as well as removing dangerous molecules.

“CSF is like the filtration system in the brain,” said Mark Shen, a former graduate student in the Amaral lab and now a postdoctoral fellow in Joseph Piven’s lab at UNC. “As CSF circulates through the brain, it washes away waste particles that would otherwise build up. We believe that extra-axial CSF is an early sign that CSF is not filtering and draining when it should. The result is that there could be a buildup of neuro-inflammation that isn’t being washed way.”

The study confirms earlier MIND Institute research that

showed infants with increased CSF in the subarachnoid space (near the brain’s perimeter) have increased risk of developing autism. The current study sought to validate the previous results in a larger sample of infants in the Infant Brain Imaging Study (IBIS), a national research network of institutions led by Piven at UNC, Washington University, Children’s Hospital of Philadelphia and University of Washington.

To test whether CSF might indicate increased risk of developing ASD, the researchers examined MRIs from 343 infants at six, 12 and 24 months. In this group, 221 babies had older siblings with ASD and were therefore at higher risk for autism. The other 122 subjects had no family history.

Infants who later developed ASD had significantly more subarachnoid CSF at six months than those who did not develop the condition. Among high-risk infants, those ultimately diagnosed with ASD had 18 percent more. These measurements predicted ASD in the high-risk group with roughly 70 percent accuracy.

The researchers do not know whether the CSF accumulation contributes to autism or is simply an effect from another cause and the biomarker is not sensitive enough to say with certainty that a child will develop ASD. However, the apparent link between increased CSF and autism could allow pediatricians to diagnose autism as early as possible using neuroimaging.

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RESEARCH VOLUNTEER REGISTRY

Help expand your knowledge of yourself and others

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Welcome to the UC Davis MIND Institute's Research Volunteer Registry.

This website is a registry that is designed to match potential volunteers with the MIND Institute's human research studies. Your participation in this research plays a vital role in improving awareness, understanding, prevention, care, and treatment of neurodevelopmental disorders.

[Enrolling in this registry](#) is the first step toward participating in our clinical research.

Make a Difference Advance Knowledge Find Treatment

The MIND Institute has a new research registry. The easy-to-use online system is designed to match potential volunteers with the MIND Institute’s human research studies.

Use this link: <https://vr.ucdmc.ucdavis.edu/vr/home.iface>

MIND Institute faculty members get coverage in leading news outlets



Julie Schweitzer, a MIND Institute faculty member and expert in attention deficit disorders, was quoted extensively in newspapers and

magazines in the U.S. and around the world in response to the massive sales of fidget spinners, toys purported to help children with attention problems to focus. Dr. Schweitzer, who in 2015 published a study on the role of fidgeting in attention, remarked that the toys are probably more of a distraction than an attention aid, and that scientific research on the craze is warranted. Dr. Schweitzer appeared in dozens of stories including in *Time*, *Newsweek* and *The Washington Post*.



Judy Van de Water, a MIND Institute faculty member, was featured in an article in *Newsweek* magazine about her research into finding a prenatal test for

autism. Dr. Van de Water identified eight autoantibodies made by a mother's immune system that appeared to be linked with autism risk if they crossed the placenta, and is working on a test to measure those biomarkers when a woman wants to conceive. The article explored the potential for a test to help families make family planning decisions and explored potential ethical concerns, as well.



Lead poisoning elimination goal of TENDR

An alliance of scientists, health professionals and children's advocates co-founded by MIND Institute faculty member Irva Hertz-Picciotto has recommended new national goals for protecting American children from lead poisoning.

Project TENDR has charted a course for better safeguarding children from lead poisoning within five years, eliminating lead exposures by 2020. Lead poisoning has been shown to harm neurodevelopment, leading to learning disabilities, lowered IQ and attention disorders. Project TENDR advocates published a viewpoint in *JAMA Pediatrics* in May outlining the national recommendations.

PEEAN program funded again

An anonymous donor has gifted \$150,000 to support Irva Hertz-Picciotto's Program on Environmental Epidemiology of Autism and Neurodevelopment (PEEAN), a program that plays a leading role in discovering modifiable causes of developmental impairments and to open the door to mitigating them.

PEEAN donations already have funded research into flame-retardant chemicals as a risk factor for autism spectrum disorder in children, and the new donation will be used to recruit a talented early career scholar to do similar work.

"The donation is particularly important to us because federal grants to help train young epidemiologists are very limited," Hertz-Picciotto said. "Further work on flame retardants, pesticides, metals and other chemicals, as well as mechanisms by which they operate to disrupt normal nervous system development is planned."

Donations provide essential funding to help enhance research to better understand how exposure to environmental factors affects child development and, ultimately, reduce the incidence of autism and other neurodevelopmental disorders.



Program for Transition into Adult Life fund established

Thanks to a \$100,000 gift from the Canel family, the Program for Transition into Adult Life is closer to becoming a reality. The fund will help develop a program that addresses the complex and pressing needs of people with neurodevelopmental disorders in their transition from school to adulthood.

The fund will support a partnership between the MIND Institute and families who together will develop programs to better prepare students and parents for the transition from school. With the clinical and research expertise of the MIND Institute, families will work with clinicians and researchers to create models of service coordination in adulthood that ensure that families can create and implement an individualized “life plan” from a menu of options. They also will investigate and document the efficacy of innovative programs in the areas of post-secondary education, vocational training and employment, and housing, identifying barriers to and facilitators of those programs.

Ultimately, program leaders hope to create a national clearinghouse for disseminating information about transition into adult life to families throughout the country and to advocate

for policy changes that can bring promising approaches to scale at local and national levels.

“There is a tremendous need nationally for research on how to best support adults with neurodevelopmental disorders and their families to improve quality of life and independence,” said Leonard Abbeduto, director of the MIND Institute. “I want the MIND Institute to be a leader in this area and to be an agent of change, and the Canel gift will put us on that path.”

“The great strength of the MIND Institute is its dedicated and innovative researchers,” said Scott Canel. “Our objective was to provide seed money to those researchers as they tackle the gaping hole in the provision of services to developmentally disabled individuals after they turn 22 and age out of the school system. Through the efforts of the MIND researchers, we hope to assist developmentally disabled young adults to transition to safe, happy and meaningful lives in the post-school world, while at the same time establishing a protocol of best practices that can be used in conjunction with advocacy efforts in every state.”

Lynda and Scott Canel, with their children, Jonathan and Lindsey, are longtime supporters of the MIND Institute. The Canel family was introduced to the MIND Institute by Randi Hagerman, as their daughter has fragile X syndrome. The Canel family has collaborated with Randi and Paul Hagerman and Len Abbeduto for more than 16 years to improve the lives of families and individuals with fragile X. Lynda and Scott served on the National Fragile X Foundation Board of Directors for over ten years, and Lynda has been a member of the MIND Institute’s National Council of Visitors since 2013.

Innovative Research Fund established for FMR1-related disorders

The MIND Institute has established a new philanthropic fund specifically for pilot research studies for novel treatments and therapeutics related to FMR1-related disorders including fragile X syndrome, fragile X-associated tremor/ataxia syndrome (FXTAS), fragile X-associated primary ovarian insufficiency and other fragile X permutation carrier disorders.

The monies will be used to pay for research infrastructure including the work of study coordinators and travel assistance for participating families.

The fund already has received generous support including \$150,000 from a Florida family and \$125,000 from an anonymous donor.

Under the leadership of Randi Hagerman, the Fragile X Research and Treatment Center is working to find breakthroughs to transform the lives of people with FMR1-related disorders.

“We are dedicated to scientific discovery targeting effective treatments, making innovative clinical care available to all families and finding a cure,” Hagerman said. “We are working hard to make this vision a reality.”

Donations are essential to continue the important work being done by Dr. Hagerman and the fragile X team – work that is revolutionizing our understanding and treatment of this multi-generational set of disorders.

Summer research program established to honor families

With a \$50,000 pledge, Arlene and Jeffrey Cohen of Scottsdale, AZ, and their extended family have established the Rosen-Weingarden Student Summer Research Program at the MIND Institute.



Pictured above, from top to bottom, left to right:

A: Paul Hagerman, Josh Cohen, Randi Hagerman and Alli Cohen

B: Mel and Monnie Weingarden

C: Enid and Bill Rosen

D: Josh, Jeff, Arlene and Alli Cohen.

The program will help introduce undergraduates, graduate students and those in professional training programs to fragile X research. Each year, the fund will provide up to four summer student research awards of \$2,500 each, to begin next summer.

“It is important to encourage talented young scholars to commit to careers focused on better understanding fragile X so we can continue to make progress discovering more effective treatments,” said Leonard Abbeduto, director of the MIND Institute. “This gift will help make that happen.”

The family established the fund because the Cohens’ twins, Josh and Alli, were diagnosed with fragile X syndrome in 1994. The diagnosis led the family to Randi Hagerman, who has supported the family with care and guidance ever since.

“Randi changed our lives, and we wanted to repay her in some way,” Jeffrey Cohen said. “We’ve become dear friends, we are like family. Establishing the Rosen-Weingarden Student Summer Research Program at the MIND makes us feel like all is right with the world.”

The fund honors the memory of Arlene’s father and mother, Bill and Enid Rosen, and also Enid’s sister Monnie, and her husband Mel Weingarden.

“The two families grew up together like the Mertzs and the Ricardos,” said Arlene Cohen, in reference to the Lucille Ball TV show of the past.

“From the start, our extended Rosen and Weingarden families embraced us, our kids and the greater cause of advancing fragile X research,” added Jeffrey. “Naming this fund to honor them acknowledges that without their love and support we wouldn’t have made it.”

The Cohens are also committed to the telling and retelling of Bill’s story.

“My dad wasn’t just the carrier who passed the gene to me, he was a mosaic male who had both the full and the premutation,” said Arlene. “No one knew it until he was 75 years old. He had challenges, but he gravitated toward his strengths. He lived the American dream and was married to my Mom for 55 years. He was a war hero, had a productive work-life, a loving family, took summer vacations and put his kids through college. Just because someone is diagnosed with FX, we cannot automatically expect less and close doors before they’re ever opened.”

Jeffrey continued, “Arlene and I see her Dad’s story as one capable of inspiring optimism and hope. Nobody has a crystal ball to see their kids’ future. Doctors are likely to tell newly diagnosed parents all about everything they think their kids will never do, but the story of Bill proves just the opposite. We are so proud to keep his story alive and to share the hope.”

For this fund, Arlene and Jeffrey represent the Rosen side of the family, which includes Arlene’s brothers Norm and Terry Rosen (and wife Candy) and their extended families. The Weingarden’s daughter Cindy (and husband Melvin Schwartz) represent the Weingarden side of the family, which includes Monnie and Mel’s two additional daughters Carrie (and husband Roger Kushner) and Ronne (and husband Jerry Acker) along with all of their extended families.

Summer news briefs at UC Davis MIND Institute



Families visiting the MIND Institute for clinic and research visits will be able to enjoy a new 4-person arcade game thanks to the generosity of Dream Arcade owned by Michelle and Mike Ware. Dream Arcade is an arcade manufacturer located in Rancho Cordova, CA. Pictured above are Nick and Michelle Ware.



Expanded Camp MIND a success

After a successful pilot last summer, Camp MIND expanded in 2017 with four summer sessions for children ages 6 through 12 diagnosed with a neurodevelopmental disorder.

Each session served 12 children, giving campers a chance to meet new peers and participate in a variety of recreational activities to promote friendships and build self-confidence.

Through group games, crafts, music and dance therapy, yoga and outdoor activities, campers learned how to make new friends, give and accept compliments, use self-control, manage stress, be a good sport and work as part of a team.

“This is a safe environment where kids with autism can make friends and learn social skills while having fun,” said Erin Roseborough, a certified child life specialist and director of Camp MIND. “We wanted this to be recreational and social.”

Roseborough started Camp MIND last year as a one-week pilot project with co-worker Caitlin Jensen, also a child life specialist.

“I was looking for camps for my daughter Brooklyn, and couldn’t find any that were affordable and designed for kids with autism,” Roseborough said. “After the pilot, we got a great reception from parents and kids, so we expanded the program this year.”

Feedback from this year’s camp was equally positive. Kirsten Spall, whose 10-year-old son Robert was diagnosed with attention deficit hyperactivity disorder and attended Camp MIND, said the camp helped build his confidence.

“It’s important for Robert to connect with others who are similar to him, and it’s hard to do this at school,” Spall said. “This gave him a chance to make friends and feel accepted and successful at the end of the day. It’s also important for parents to feel successful, and know that someone can work with their child. This has been a good opportunity for us.”



On Friday June 9th, Supreme Officers and Past Pharaohs of the Scouts visited the UC Davis MIND Institute to learn more about its mission and to present a \$5,000 check and plaque on behalf of the Scouts Foundation. Pictured L-R: Bill Hunt; Steve Munyon; Scouts Foundation president Bud Ramsey, P.P.; Randi J. Hagerman, M.D.; Clive Moss, P.P.; Elizabeth McBride, Director of Development; John Sigismondi and Chuck Mignosa, P.P.

How you can make a difference

Join us as a donor, research participant or volunteer and help us improve the quality of life of people and their families living with neurodevelopmental disorders.

Donations of all sizes make a difference, and you may direct your support to the area that matters most to you. Donating is easy. You can give online, by check or even payroll deduction through United Way or your employer's giving campaign. To make a donation, contact Elizabeth McBride at ekmcbride@ucdavis.edu or 916-703-0221 or visit give.ucdavis.edu/MIND.

Our new online research registry gives volunteers the opportunity to participate in various research studies that play a vital role in improving awareness, understanding, prevention, care and treatment of neurodevelopmental disorders. Go to <https://vr.ucdmc.ucdavis.edu/vr/home.iface> and click on the "Register Now" button and follow the prompts to register yourself or family members.

Volunteers are essential members of our team and have the opportunity to assist in our Child Life Program, Research Clinic and our Resource Center. Visit our website for more information: mindinstitute.ucdavis.edu/giving/volunteer/index.html.



Message from the director

We always strive to do more to help families affected by neurodevelopmental disorders.

Sometimes this

means continuing what we do well.

For example, our scientists continue to tackle questions about the causes of, and treatments for, neurodevelopmental disorders. Our physicians, psychologists and other clinicians also diagnose, treat and support families in the Massie Family Clinic, and work in ways that bring more families to us to be helped.

Sometimes doing more means looking for gaps and filling them, or tackling problems in innovative ways. In the past few months, gifts from visionary donors have enabled us to fill gaps and innovate.

We recognized a growing need to develop and document the efficacy of programs to support individuals with neurodevelopmental disorders as they move from school to adult life. What types of programs and supports help them secure meaningful and appropriate employment, live more independently, develop meaningful peer and romantic relationships, and participate fully in their communities? The Canels' generous gift to our new Program for Transition to Adult Life provides seed funding for research and will help us recruit more scientists interested in addressing issues of transition and adult life.

Declining federal health budgets have made it more difficult to obtain research funding and to train the next generation of scientists. And state support for many public universities is also strained. So, we need additional funding sources for training to maintain progress in understanding and treating neurodevelopmental disorders. We are grateful for a gift from the Cohen family to support a summer fellowship program for undergraduate and graduate students interested in fragile X syndrome and FMR1-related disorders research.

The path from an exciting idea to clinical trial can be long and arduous, and particularly frustrating when the idea concerns a new drug or other treatment that may improve lives. So we were thrilled to receive a gift to launch our Innovative Research Fund for FMR1-related Disorders. This fund will provide immediate seed funding for innovative, promising treatment research and clinical trials and help speed the process of securing NIH or other funding for a larger and, hopefully, definitive study.

We are excited about the opportunities created by our donors' vision and generosity and the potential benefits to the families who depend on us. Thank you, and enjoy the remaining days of summer.

Leonard Abbeduto
Director, UC Davis MIND Institute