The UC Davis MIND Institute has established a new National Council of Visitors, a group of nationally and internationally respected leaders who are enthusiastically committed to support of the MIND Institute’s mission of advancing research into the causes of and treatments for neurodevelopmental disabilities, and to ensuring superior patient care to individuals diagnosed with these conditions. The council held its first meeting in fall of 2013.

The council’s goals are to:
- Promote the MIND Institute nationally and internationally
- Initiate and contribute ideas, expertise and influence
- Strengthen relationships with diverse communities served by the MIND Institute
- Secure support for the MIND Institute by making personal commitments and identifying others who can and will make a significant philanthropic gift to the institute

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My gift: Claudia Huntington

A decades-old friendship and her experience with a family member with intellectual disabilities catalyzed a gift from Claudia Huntington to the Center for Excellence in Developmental Disabilities (CEDD) at the UC Davis MIND Institute.

Huntington is senior vice president, portfolio manager and director of the Capital Research and Management Group in Los Angeles. She attended undergraduate school at Stanford University where, early on, she had four roommates. They would remain lifelong friends. One was Robin Hansen, who would become director of the CEDD and chief of the Division of Developmental and Behavioral Pediatrics in the UC Davis School of Medicine.

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Members of the National Council of Visitors

**Lynda Canel** is a resident of Highland Park, Ill. She and her husband Scott have two children, one who has fragile X syndrome. Lynda discovered the UC Davis MIND Institute Fragile X Research and Treatment Center during her ongoing search for the most leading-edge treatments for her daughter. Lynda also served for 10 years on the board of directors of the National Fragile X Foundation with MIND Institute Medical Director Randi Hagerman, through whom she became familiar with the MIND Institute and Randi and Paul Hagerman’s fragile X investigations. Lynda is committed to her daughter’s care and has made a personal philanthropic commitment to the MIND Institute to support fragile X research.

**Chrysa Demos** is a resident of Stony Brook, N.Y., and a Sacramento native. Her parents, Angelo and Sofia Tsakopoulos, established the Tsakopoulos-Vismara Endowed Chair, held by the Executive Director of the MIND Institute and are one of the MIND Institute’s Founding Families. Chrysa’s personal connection to the MIND Institute stems from her deep respect and admiration for Dr. Louis Vismara. Chrysa has been a dedicated member of the local MIND Advisory Council for several years and she remains committed to supporting the philanthropic efforts of the MIND Institute throughout the East Coast region. Chrysa served as vice president of AKT Development Corporation, the largest land development company in Sacramento.

**Sarah Gardner** is a resident of Sacramento, Calif. She and her husband Chuck are among the MIND Institute’s founding families. Sarah and Chuck are the parents of two children, one of whom, their son, has autism. A former news anchor for KCRA Channel 3, Sarah has been a member of the MIND Institute Advisory Council since 2007. During more than a decade of involvement and as a Founding Family member, Sarah has been an enthusiastic advocate for and leader of philanthropic efforts on behalf of the institute. Sarah remains committed to the institute’s mission of finding treatments, causes and prevention for autism and other neurodevelopmental disorders.

**Gail Goldstein Heyman** is a resident of Marietta, Ga., and is the president and co-founder of the Fragile X Association of Georgia. Her longtime career as a dental hygienist inspired her passion for service and community activism. Gail serves on several local and national boards and has been recognized by many organizations for her service. She and her husband, Lyons Heyman, Jr., became involved with efforts to support fragile X research when their adult son, Scott, was diagnosed with fragile X syndrome as a young boy. Through an interesting fusion of dentistry and medical research, Gail and her family made a unique personal contribution to fragile X research by donating her son’s extracted wisdom teeth for the purpose of stem cell research for fragile X syndrome. Gail enthusiastically shares the MIND Institute’s vision to uncover the causes of, and find new and more effective treatments for, neurodevelopmental disorders such as fragile X syndrome.
Holle McRae is a resident of Caldwell, Idaho. She and her husband Lon have four children, including a son with chromosome 22q11.2 deletion syndrome. Holle is a former member of the UC Davis MIND Institute Parent Advisory Council for chromosome 22q11.2 deletion syndrome research. Motivated by the critical need for a safe and flexible educational environment for her son, she and her husband were the driving force behind the establishment of Heritage Community Charter School in Caldwell, where Holle is the current vice chairman of the board of directors. Holle is a dedicated parent who is committed to supporting the MIND Institute’s efforts to find new and more effective treatments to improve the lives of individuals and families with chromosome 22q11.2 deletion syndrome.

Luis Navas is a resident of Miami, Fla. He holds the position of vice chair at Global Governance Advisors, an internationally known independent compensation advisory firm. Luis and his wife Mary have two children. Their son was diagnosed with autism at the age of 2. His personal experience with autism and deep understanding of the challenges families face inspire Luis’ philanthropic passion. In partnership with his colleagues, Luis raised $2 million to purchase a luxury vacation home on Florida’s beautiful Emerald Coast. The home serves as a special getaway for families in need who have children on the spectrum. Luis is committed to raising awareness and providing critical support and services to individuals and families affected by autism.

Pedro Reyes is a resident of Davis, Calif., and is the director of the California State Assembly’s Speaker’s Office of Research and Floor Analysis. Previously he was chief deputy director of the California Department of Finance. Pedro is an alumnus of the UC Davis College of Agricultural & Environmental Sciences. He has a grandson on the autism spectrum. Pedro joined the MIND Institute Advisory Council in 2012. He is a proactive and dedicated advocate, sharing the work of the MIND Institute with his social and business contacts. Pedro and his wife Esther also have provided philanthropic support to the institute to support autism research.

Neal Robb is a resident of Manhattan Beach, Calif. He is a litigator specializing in defending financial services firms, handling large and complex litigation. Neal and his wife Carolyn have a son who has been diagnosed with fragile X syndrome and autism. Neal is a former director and two-term president of the Fragile X Association of Southern California. Neal and Carolyn are very active in charitable organizations in their community and with the Manhattan Beach School District. Neal is a committed parent who is dedicated to the mission of the MIND Institute to find the causes of and new and more effective treatments for neurodevelopmental disorders.

Michelle Montna Vogt is a resident of Woodland, Calif. She and her sister Nicole help manage their family’s rice farm, Montna Farms, located in Yuba City, Calif. The farm sits on land that has been in Michelle’s family since the 1800s. Michelle and her husband Casey have four children. At age 3 their son was diagnosed with autism and was evaluated at the MIND Institute. Today her son is an active 7 year old, participates in the MIND Institute social skills program, and is making great progress. Michelle’s mother, Gail Montna, is an active member of the MIND Institute Advisory Council. Michelle and her family are committed to finding the best treatments and therapies for individuals with autism. To help support the advancement of autism research, the Montna family has made a personal philanthropic commitment to the MIND Institute.
Huntington is particularly committed to the crucial program her college friend leads at the MIND Institute.

“I’m very emotionally committed to the work that Robin has spent her life doing,” Huntington said. “I admire it. I think it’s really important. There are children and families whom Robin is helping enormously.”

And there is another, also personal, reason for her gift with her husband, Marshall Miller.

“I have a half sister who is a good deal older than I who has intellectual disabilities, so I’m quite sensitive to the difficulties of living with a child with a disability. It’s so hard for families, and for the individual to have a good quality of life.

“So when Robin asked me if I’d be interested in helping out, I said yes.”

Hansen said that her friends Claudia and Marshall’s philanthropic gift to the CEDD is emblematic of their generosity of spirit and commitment to helping others.

“Over the years, Claudia has been an important touchstone in my life, and her interest in my work has been a constant,” Hansen said. “This gift to support our work at the CEDD has special significance for us both and will help to create more opportunities for rich, inclusive lives for individuals with developmental disabilities.”

Housed at the MIND Institute, the Center for Excellence in Developmental Disabilities collaborates with individuals with developmental disabilities and their families to improve their quality of life and community inclusion through advocacy, community partnerships, interdisciplinary training, and the translation of research into practical applications. The center is one of 67 University Centers for Excellence in Developmental Disabilities (UCEDDs) nationwide that support early intervention, health care, community-based services, inclusive and meaningful education, transition from school to work, employment, housing, assistive technology, and transportation, among other initiatives.

“ITM very emotionally committed to the work that Robin has spent her life doing. I admire it. I think it’s really important. There are children and families whom Robin is helping enormously.”

~ Claudia Huntington
While they normally inhabit different alternate universes, on Dec. 7, Imperial Stormtroopers and C-3P0 from Star Wars, characters including The Doctor from Dr. Who and minions from Despicable Me all got together for a good cause: the MIND Institute’s annual party to thank children and their families who participate in groundbreaking research on neurodevelopmental disorders such as autism, fragile X syndrome, attention-deficit/hyperactivity disorder (ADHD), Down syndrome, and chromosome 22q11.2 deletion syndrome.

The outer space/science fiction themed event, ‘A Mission to Fun,’ featured bounce houses and outdoor activities – among them a three-story inflatable space shuttle slide. Live performances included a presentation and question-and-answer session with a real astronaut, Stephen Robinson, a veteran of four space shuttle missions who now is a professor in the university’s Department of Mechanical and Aerospace Engineering.

The annual event is a labor of love for the MIND Institute’s faculty, staff and a legion of volunteers, who work tirelessly to provide a fun and welcoming environment for the families who make its internationally respected research possible.

Jackie Zuvella of Cool, Calif., brought her two adopted daughters, Juliette, 10, who has autism spectrum disorder, and Camille, 8. Juliette has participated in three research studies, including a study on autism and sleep anomalies and using virtual reality for social skills training in children with autism.

Zuvella said that her family’s involvement in the MIND Institute has been a godsend. Early on, Juliette would scream and take off all of her clothes and run around the house. Her family tried everything they could to help her.

“But it wasn’t until we went to the MIND Institute and got the diagnosis that we were able to get in-home behavioral therapy for our daughter through the regional center,” Zuvella said. “I just know that, without their help with diagnosing my daughter, I would be sitting in a corner and rocking myself right now. And the studies help me know better how to help Juliette.”

Nicole and Chris Neff of Vacaville, Calif., brought their two children, Rayna, 6, and Nathan, 2, to the event. Rayna has autism and has participated in the Childhood Autism Risks from Genetics and the Environment (CHARGE) Study. When Nicole learned she was pregnant with Nathan she participated in the Early Autism Risk Longitudinal Investigation (EARLI) Study, which enrolls expectant mothers. Participation in EARLI told the Neffs that their 2-year-old son is developing typically.

Rayna did not crawl until she was 16 months old; she did not begin to walk until 26 months. A comprehensive assessment at the MIND Institute allowed the Neffs to press their regional center to obtain services for their daughter, including in-home behavioral therapy, speech and occupational therapy.

“Rayna is doing so much better with the ABA therapy, speech and occupational therapy. And it has been a big relief to know that Nathan is developing typically,” Nicole Neff said.

David Amaral, director of research at the MIND Institute, said it is a delight to be able to give a few hours of fun and joy back to the families who enable its research.

“The MIND Institute research thank you party is made possible by dedicated faculty, staff and students, over 150 volunteers and 140 donors of gifts and services for participating families,” Amaral said. “It is one opportunity when we can express our gratitude for the collaboration and trust that our community places in the MIND Institute.”
How you can make a difference

You can advance medical treatment through our innovative research by making a philanthropic gift to the UC Davis MIND Institute. Your support will directly help the millions of individuals and families living with the challenges of neurodevelopmental disorders. Please consider making a gift to help improve the lives of our patients now and in the future.

For more information on how you can support the UC Davis MIND Institute please contact Development Director Bob Stout at 916-717-2749 or at robert.stout@ucdmc.ucdavis.edu.

I n this New Year, I want to express my deepest gratitude to all of our friends who have made gifts to the MIND Institute to advance the cause of improving the lives of people with neurodevelopmental conditions. They and their families are at the heart of everything we do, from our research and clinical enterprise to our community outreach and support activities. I am particularly excited that some of those parents who also are donors have agreed to help amplify and guide our fundraising efforts through our new National Council of Visitors. Going above and beyond their own gifts, the members of the National Council of Visitors have made the additional commitment to take our fundraising to new heights, nationally and internationally. They are donors and advocates from throughout the country who have family members with autism, fragile X syndrome and 22q11.2 deletion syndrome. I was honored to bring them together at the MIND Institute last fall for our first, and very fruitful, meeting. I look forward to their collaboration, advice and counsel, and to growing their ranks. I will share their activities in the pages of this newsletter. Again, thank you for your generosity. I wish you and your families a safe, prosperous and Happy New Year!

Leonard Abbeduto
Tsakopoulos-Vismara Endowed Chair, Psychiatry and Behavioral Sciences Director, UC Davis MIND Institute

Happy New Year!