Joyce Raley-Teel and Jim Teel, co-chairs of the Raley’s Family of Fine Stores, are well known for their concern for the welfare of children and families in the Sacramento region and beyond. So it was not a surprise when the couple, who are legendary for their warmth and generosity, extended their concern to children and adolescents with autism spectrum disorder.

Where better to make a difference in those children’s lives than at the MIND Institute, through its highly regarded social skills program, led by Marjorie Solomon, associate professor of clinical psychiatry and behavioral sciences.

Solomon said that the Teel’s gift was the fountainhead that nearly doubled the number of young people whom she can help. And more advances lie ahead because of the gift, Solomon said.

“We have been able to expand into a much larger program, and that has been really wonderful,” she said. “Their generosity has been the stepping stone that has allowed us to improve our staff training, so that we can include kids who aren’t as high-functioning. And their gift was the spark for a new social skills group for adults’ that will begin early in 2015.

Randi Jenssen Hagerman receives C. Anderson Aldrich Award

Randi Jenssen Hagerman, medical director of the UC Davis MIND Institute, Distinguished Professor of Pediatrics and Endowed Chair in Fragile X Research and Treatment, has received the prestigious C. Anderson Aldrich Award in Child Development for her outstanding contributions in the field of child development from the American Academy of Pediatrics (AAP), the professional organization for pediatricians in the United States.

The award recognizes pediatricians and non-pediatricians for their respective contributions to the field of developmental and behavioral pediatrics. It was presented at the American Academy of Pediatrics Section on Developmental and Behavioral Pediatrics national conference in San Diego on Oct. 12, 2014.

“I am greatly honored by this award, humbled after reading the list of previous recipients, and pleased that the AAP recognizes the importance of targeted treatments for individuals with neurodevelopmental disorders,” Hagerman said.
Establishing new tests to evaluate cognitive growth in people with intellectual disability

Tests will track improved thinking and problem-solving skills in people with fragile X, Down syndromes, and other intellectual disabilities

Researchers with the UC Davis MIND Institute will develop and evaluate tests designed to measure and track changes in the cognitive functioning of people who typically are difficult to assess accurately: those with an intellectual disability, formerly termed mental retardation. The research will be funded through a new, five-year, $3.2 million grant from the National Institutes of Health (NIH).

The effort will be paired with other research conducted at the MIND Institute and elsewhere, which seeks to evaluate the efficacy of new, investigational treatments for people with intellectual disability. The tests will eventually be used to ascertain the effectiveness of medications and other treatments, specifically for people with fragile X and Down syndromes and other intellectual disabilities. Fragile X and Down syndromes are among the leading causes of intellectual disability in the United States and around the world. Fragile X syndrome also is the leading single-gene cause of autism spectrum disorder.

At the MIND Institute, the research will be led by principal investigator David Hessl, professor in the Department of Psychiatry and Behavioral Sciences and director of the Translational Psychophysiology and Assessment Laboratory, and co-investigator Leonard Abbeduto.

“There are virtually no comprehensive and developmentally appropriate, well-validated and reliable cognitive measures suitable for tracking treatment responses in people with intellectual disability,” Hessl said, “but there are exciting new therapies being evaluated now and more on the horizon, which suggests that substantial gains in cognitive functioning are possible, even for adults with lifelong cognitive deficits.”

“Most currently available standardized tests have been developed mainly for the general population and are not well-suited for people with intellectual disabilities,” he said. “They just weren’t designed for people with the level of functioning we typically see in fragile X and Down syndromes. What we will be working to do is modify and then validate the NIH Toolbox Cognition Battery so that it works well for individuals with intellectual disability.”

The NIH Toolbox is a multidimensional set of brief measures assessing cognitive, emotional, motor and sensory function from ages 3 to 85, meeting the need for a standard set of measures that can be used as a common currency across diverse study designs and settings. The cognitive test battery used in the study is a computer-based set of tests tapping processing speed, memory, attention and language.

The research will be conducted in concert with three other leading research institutions with robust programs in intellectual disabilities. At three other universities are involved:

- Karen Riley, dean and associate professor, Morgridge College of Education, The University of Denver;
- Richard Gershon, associate professor, medical social sciences and preventive medicine-health, Northwestern University School of Medicine;
- Elizabeth Berry-Kravis, professor, biochemistry, neurological sciences, pediatrics, Rush University Medical Center, Chicago.

“This project will help address a critical problem that is one of the largest barriers to development of new treatments to modify the underlying disease in developmental disabilities – the lack of good measures to document improvement in thinking that are appropriate, valid and measure change in children and young adults with intellectual disabilities,” Berry-Kravis said.

The research will benefit a wide range of studies aiming to assess or improve specific areas of cognition in persons with intellectual disability, Hessl said.

To evaluate the reliability, validity and sensitivity of the battery, over a five-year period the MIND Institute, Rush University and The University of Denver each will enroll 150 individuals with intellectual disability between the ages of 6 and 25 years with either fragile X syndrome, Down syndrome,
Larry Krantz

Larry Krantz is a resident of Bronxville, N.Y. He is the founder of the New York law firm of Krantz & Berman LLP, where he currently represents public and private companies in both criminal and civil matters. Prior to founding Krantz & Berman, Larry was a federal prosecutor and has over thirty years of trial and appellate litigation experience. He has been involved in numerous high-profile cases and has successfully tried a wealth of criminal and civil cases in federal and state courts. Larry’s relationship with the MIND Institute and Dr. Randi Hagerman, Medical Director and Endowed Chair in Fragile X Research, developed long ago from his own personal experience with fragile X syndrome. Larry is the father of a 17-year-old son who has been diagnosed with fragile X syndrome. He also has a 19-year-old daughter whose life has been affected by fragile X. For many years, Larry and his family have been generous supporters of the innovative fragile X research conducted at the Institute. Larry remains committed to supporting the mission of the MIND Institute and to helping to move forward the discovery of new and more effective treatments for fragile X syndrome and related neurodevelopmental disorders.

Leah Strevalia

Leah Strevalia is the newest member of the MIND Institute’s National Council of Visitors. She is an attorney whose professional career has been focused around health-care advocacy for the disenfranchised, first in Washington, D.C., and later in the San Francisco Bay Area. Leah has worked as a government relations representative for the American Foundation for AIDS Research (amFAR), where she was a voice for the need to advance AIDS research, prevention, treatment and care for people living with HIV and AIDS in the United States and around the world. She later brought her expertise to the Alameda County Health Consortium, where she worked to ensure funding for the medically underserved and uninsured, particularly at a consortium of community-based health centers. Leah came to Sacramento in 2013 with her husband, Pete D’Alessandro, the general manager of the Sacramento Kings professional basketball franchise. She is the mother of two young children, Kate, 5, and Benjamin, 3. She attended Smith College and Georgetown University Law Center.

Fundraising: A record-breaking year

The 2013-14 fiscal year was among the most successful in the UC Davis MIND Institute’s history, with more than $2.5 million raised. That amount is more than double last year’s efforts, and more than five-fold what was raised in fiscal year 2010-11. Gifts for autism research lead the institute’s fundraising efforts, at nearly $1 million. Gifts for fragile X research garnered more than $630,000. These donations came from around the country and the world, from as far away as South America, Europe and Asia. All told, these gifts represent a year of record-breaking donations, both in the total amount of the gifts and the number of new donors. We are especially thankful for the invaluable ongoing support of the National Council of Visitors, including Lynda Canel and Gail Heyman for fragile X and Michelle Vogt and Pedro Reyes for autism.

2014-15 DISTINGUISHED LECTURER SERIES

February’s Distinguished Lecturer Series will feature Jeremy Veenstra-VanderWeele, of Columbia University, speaking on “Pathways for Treatments in Autism Spectrum Disorder”.

For more information, visit mindinstitute.ucdavis.edu.
"Joyce and Jim really inspire me because of their philanthropy and love of helping people, and because, in spite of their incredible means and stature, they are warm, caring and down-to-earth people," Solomon said.

The Teels recently attended a reception in their honor at the UC Davis MIND Institute, to celebrate the naming of the Joyce and Jim Teel Executive Board Room, a gift of the Thomas P. Raley Foundation. They were joined at the event by more than 20 members of their family.

In attendance were Linda P.B. Katehi, UC Davis chancellor; Julie Freischlag, vice chancellor for Human Health Sciences and dean of the School of Medicine at UC Davis; Shaun Keister, UC Davis vice chancellor for Development and Alumni Relations; Chong Porter, associate vice chancellor of Health Sciences Development and Alumni Relations; and Leonard Abbeduto, MIND Institute director.

“My granddaughter, Brooke Davidson, is pursuing a career in the autism spectrum disorder field and had a wonderful experience working at the MIND Institute with Dr. Marjorie Solomon. Our family supports research and treatment for this worthy cause and hopes a cure one day will be found,” Mrs. Teel said.

“The MIND Institute was created by families to provide help and hope to families affected by autism and other neurodevelopmental disorders,” Abbeduto said. “The gift from the Teels is particularly fitting, given their long-standing commitment to the welfare of Sacramento area families. We are especially pleased that they have chosen to give to the social skills program, which is a signature program for us, and one that we have long wanted to grow and make available to even more families in need. The Teel gift allows us to do that.”

The Raley’s Family of Fine Foods operates more than 120 stores in California and Nevada, including the Raley’s, Bel Air Markets, Nob Hill Foods and Food Source stores. The business was started by Thomas Raley, who opened the first store in Placerville in 1935. Today the Teel’s son, Michael, serves as chief executive officer. With Raley’s chief executive officer emeritus Charles Collings, the Teels established Food For Families, a non-profit organization that provides food for the needy that has helped raise over $31 million and donated over 21 million pounds of food to fight hunger.

**Hessl research**

or intellectual disability of unknown cause. The participants will undergo one round of testing and a second round four weeks later. The overall growth in the participants’ intellectual skills will be tested again after two years.

The Northwestern University team, which is responsible for the development, maintenance and training of the NIH Toolbox, will assist with making modifications to the tests to suit this unique population, maintain the data generated from the study, and participate in interpreting and disseminating the study findings.

“The holy grail of intellectual disabilities research is to find a treatment that raises a person’s cognitive capacity, and consequently their ability to function better on a day-to-day basis,” Hessl said. “To prove that a treatment does that, you have to have tests that are sensitive to actual changes, including those associated with treatment.”
Hagerman award

Hagerman is an internationally recognized clinician/scientist, director of the clinical trials program and founder of the Fragile X Research and Treatment Center at the MIND Institute. In 2001, with her husband Paul J. Hagerman, UC Davis Distinguished Professor of Biochemistry and Molecular Medicine, she discovered fragile X-associated tremor/ataxia syndrome (FXTAS), a neurological disorder that affects older carriers of the fragile X premutation. In 1984 she co-founded the National Fragile X Foundation.

“This award is well-deserved recognition for Dr. Hagerman’s lifelong commitment to children with fragile X syndrome and their families,” said Leonard Abbeduto. “She has helped thousands of people directly through her clinical care, and countless more through her groundbreaking research on the causes, consequences and treatment of FMR1-related disorders.”

“She also has trained and mentored a generation of pediatricians who will carry the field forward for decades to come,” Abbeduto continued. “It is certainly fitting that Dr. Hagerman is added to the list of luminaries who have received this award before her.”

Randi and Paul Hagerman

The C. Anderson Aldrich Award is one of the most prestigious in the field of pediatrics and includes such earlier recipients as T. Barry Brazelton, Anna Freud, Leo Kanner, Erik Erikson and Sir Michael Llewellyn Rutter. Hagerman has received numerous other awards for her research in fragile X syndrome, including the Jerrett Cole Award from the National Fragile X Foundation for unselfish dedication to work with fragile X children and adults; the Bonfils-Stanton Foundation Award for Science including Medicine; the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSID) Distinguished Achievement Award for Scientific Literature; the 2014 Distinguished Scholarly Public Service Award from the UC Davis Academic Senate; and the 2006 Dean’s Award for Outstanding Mentoring at UC Davis.

In 2004, to honor Randi and Paul Hagerman for their work in FXTAS, the National Fragile X Foundation established the Hagerman Award, which recognizes research accomplishments in the field of FXTAS. In 2008 the National Fragile X Foundation again honored Randi Hagerman with a Lifetime Achievement Award.

Hagerman has worked to establish fragile X clinical and research programs throughout the world, most recently at a fragile X hotspot in Ricuarte, Colombia. She currently is carrying out multiple targeted treatment trials in fragile X syndrome and in autism.

Hagerman has written over 300 peer-reviewed articles and written or edited numerous book chapters or books on neurodevelopmental disorders including: A 3rd Edition of Fragile X Syndrome: Diagnosis, Treatment, and Research (2002) and Treatment of Neurodevelopmental Disorders: Targeting Neurobiological Mechanisms (2014) with Robert Hendren of UC San Francisco.

How you can make a difference

You can advance progress toward treatments 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 the MIND Institute development office at 916-703-0221.
Hundreds of families streamed into the UC Davis MIND Institute on Dec. 6 for the 12th Annual Thank You Party, an event cherished by families of children with disabilities that acknowledges their role in making the institute’s groundbreaking neurodevelopmental research possible. The great outdoors-themed event had something for everyone, from costumed superheroes such as Captain America, Wonder Woman, and Spiderman, to animated favorites from popular family films such as “Frozen” and “Winnie the Pooh.”

The fantasy characters were joined by real-live animals, including an alligator, python, and an Australian animal called a kinkajou, all courtesy of Wild Things, Inc. The wildlife theme continued with entomologists – and their bugs – from UC Davis’ own Bohart Museum of Entomology, where kids could reach out and touch a real-live millipede or walking stick, among other creepy crawlies, in the bug petting zoo.

For many of the children, who have conditions such as autism, fragile X syndrome, and Down syndrome, there are few places where they can be fully included in activities just like their typically developing peers. There were towering bounce houses where kids could get their wiggles out, a miniature train ride to climb aboard, and a climbing wall for the truly adventurous.

This year, more than 150 volunteers worked tirelessly for months to make it come together, all shepherded by Erin Roseborough, the MIND Institute’s child life specialist and volunteer coordinator. Each year, the army of volunteers turns the institute into outer space, or a woodland playground, or a winter wonderland, depending on the theme. Volunteers come from UC Davis undergraduate clubs and fraternities, the National Charity League, and Capitol Autism Services, among others.

“We are so happy that we are able to serve our families and give them the opportunity to participate in an event where they can have fun and be entertained in a safe and accepting environment,” Roseborough said.

The annual labor of love relies heavily on donated goods and services. At the close of the event, the institute gave away thousands of dollars in gift baskets. Nearly 100 organizations made donations, from airplane trips on Southwest Airlines and Jet Blue, to performances at the American Conservatory Theater, UC Davis Mondavi Center and the Esquire IMAX Theater. Even the holiday trees that dotted the halls were donated, as was enough food and drink to feed nearly 1,000 guests. All told, an estimated $15,000 in donations makes the event – which has grown to become the second-largest held on the Sacramento campus of UC Davis – a reality.

“Since its inception in 2003, the Thank You Party has become a tradition at the MIND Institute,” said David Amaral, research director of the MIND Institute. “It reflects the unique partnership that the faculty, staff and trainees have with the community. It is the one time during the year that the kids just come to the MIND Institute to have fun.”
In this issue, we share the wonderful energy and vitality of the MIND Institute Thank You Party. I would like to continue this theme and take this opportunity to thank all of the generous people who have made financial gifts to our scientists, clinicians, and programs during the past year. In fact, the 2013-2014 fiscal year was one of the most successful for philanthropy since the MIND Institute complex was opened in 2003.

Many of our senior scientists and established programs had their work accelerated by generous donors. Irv Hertz-Picciotto, a world-renowned epidemiologist and professor of public health sciences, received significant philanthropic support, allowing her to advance her groundbreaking research into environmental exposures and the etiology of autism. Marjorie Solomon, associate professor of psychiatry and behavioral sciences, received several meaningful gifts that will help her change the lives of children and young adults with autism through the Social Skills Program that she directs. Randi Hagerman, MIND Institute medical director and director of the Fragile X Research and Treatment Center, received substantial philanthropic support from around the globe. She has built lifelong relationships with her patients and their families, caring for many of them from infancy and throughout their adult lives and is developing new treatments targeting the many conditions associated with the fragile X mutation.

Other esteemed programs, such as the Center for Excellence in Developmental Disabilities and the Chromosome 22q11.2 Deletion Syndrome Research Program and Healthy Minds Clinic, also have received substantial support from individual donors, foundations and corporations from around the nation.

We also plan to launch new programs in the coming years so that we can help improve the lives of many more families, and these programs will depend on philanthropic support for their success. We hope, for example, to significantly expand our research, clinical care, and education programs focused on Down syndrome, the leading genetic cause of intellectual disability. Several recent grants from the National Institutes of Health to our scientists are supporting work on the development of new methods of assessing improvement in language and cognition in clinical trials involving people with Down syndrome. We want to build on this initial success to expand the types of research we conduct on Down syndrome through a seed grant program, as well as through the recruitment of new faculty and trainees with an interest in the condition. We also intend to expand our clinical expertise in assessing and treating the behavioral and health challenges commonly associated with Down syndrome. Additional initiatives are planned in early intervention, parent training, and telehealth technology, all of which can be grown from the gifts of generous donors.

Leonard Abbeduto  
Director, UC Davis MIND Institute