Treatment update
Infant treatment alleviates symptoms of autism

Treatment at the earliest age when symptoms of autism spectrum disorder (ASD) appear – sometimes in infants as young as 6 months old – significantly reduces symptoms so that, by age 3, most who received the therapy had neither ASD nor developmental delay, a UC Davis MIND Institute research study has found.

The treatment, known as Infant Start, was administered over a six-month period to 6- to 15-month-old infants who exhibited marked autism symptoms, such as decreased eye contact, social interest or engagement, repetitive movement patterns and a lack of intentional communication. It was delivered by the people who were most in tune with and spent the most time with the babies: their parents.

"Autism treatment in the first year of life: A pilot study of Infant Start, a parent-implemented intervention for symptomatic infants," is co-authored by UC Davis professors of Psychiatry and Behavioral Sciences Sally J. Rogers and Sally Ozonoff. It is published online in the Journal of Autism and Developmental Disorders.

"Most of the children in the study, six out of seven, caught up in all of their learning skills and their language by the time they were 2 to 3," said Rogers, the study's lead author and the developer of the Infant Start therapy. "Most children with ASD are barely even getting diagnosed by then."

"For the children who are achieving typical developmental rates, we are essentially ameliorating their developmental delays," Rogers said. "We have speeded up their developmental rates and profiles, not for every child in our sample, but for six of the seven."

Rogers credited the parents in the small, pilot study with making the difference.

"It was the parents – not therapists – who did that," she said. "Parents are there every day with their babies. It's the little moments of diapering, feeding, playing on the floor, going for a walk, being on a swing, that are the critical learning moments for babies. Those moments are what parents can capitalize on in a way that nobody else really can."

Rogers' study generated phenomenal media interest, including coverage by the CBS Evening News with Scott Pelley and the NBC Nightly News with Brian Williams. The study was covered in the Wall Street Journal, TIME and Newsweek. Stories appeared all over the world, from Brazil to Norway.
Hagerman keynotes National Fragile X Foundation Conference

Nearly 1,000 individuals with fragile X-associated disorders and their families, fragile X clinicians, researchers and fragile X advocates attended the National Fragile X Foundation’s 14th International conference on Fragile X in July in Orange County, Calif., keynoted by UC Davis MIND Institute Medical Director Randi Hagerman.

“The conference was uplifting,” Hagerman said. “It gave all of us from the MIND Institute the opportunity to connect with many families, researchers and collaborators with an overflowing number of ideas and new collaborations that will carry us forward for years of exciting research.”

Hagerman provided two plenary lectures, one focused on premutation disorders, reviewing the multiple medical, endocrine and neurological problems associated with the premutation. The disorders include fragile X-associated primary ovarian insufficiency (FXPOI), anxiety, depression, fibromyalgia, neuropathy, sleep apnea, restless legs syndrome, migraines, hypertension, hypothyroidism and fragile X-associated tremor/ataxia syndrome (FXTAS). The address focused on how patients with premutation disorders can stay healthy.

Hagerman presented the second plenary session in concert with Professor Elizabeth Berry-Kravis of Rush University, Chicago. The MIND Institute and Rush have the most extensive experience treating patients with fragile X using targeted treatments. The discussion included a review of those treatments, including controlled trials of arbaclofen, a GABA-B agonist, and AFQ056, an mGluR5 antagonist, both of which have been discontinued. Newer treatments with ganaxolone, sertraline in young children and metadoxine, a stimulant-like medication, and an IGF1 analogue, in adolescents and adults with fragile X syndrome were discussed.

Other conference highlights included a workshop on early language intervention in young children with fragile X syndrome, presented by MIND Institute Director Leonard Abbeduto and Dr. Andrea McDuffie. Dr. Flora Tassone presented on newborn screening for fragile X and molecular markers of involvement, and Dr. David Hessl led a panel discussion on outcome measures for clinical trials. Dr. Susan Rivera presented on neuroimaging and eye-tracking outcome measures in young children with fragile X syndrome.

Other MIND Institute faculty and students in attendance included David Benjamin, Lauren Bullard, Marie Moore Channell, Mandeep Chela, Kerrie Lemons Chitwood, Maria Diez, Jessica Famula, Amy Gaines, Pamela Gallego, Laura Greiss Hess, Maryam Jabbari, Reymundo Lozano, Dalyir Pretto, Jonathan Polussa, Stephanie Summers, Robyn Tempero-Feigles, Angela John Thurman and Caitlyn Wong.

New book: Treatment of Neurodevelopmental Disorders

Randi Hagerman, Endowed Chair in Fragile X Research and medical director of the UC Davis MIND Institute, and Robert Hendren, professor, vice chair and director of child and adolescent psychiatry in the UC San Francisco Department of Psychiatry, are the editors of a new leading-edge book, Treatment of Neurodevelopmental Disorders: Targeting Neurobiological Mechanisms, published by Oxford University Press. The book details advances in genetics, neurobiology and psychopharmacology, and their treatment applications in clinical settings. Information about the book is available online at the Oxford University Press (oup.com/us), Amazon.com and Barnes & Noble (bn.com).
Rare Champion of Hope, 2014

Katherine Rauen, professor in the Department of Pediatrics and a physician-scientist affiliated with the UC Davis MIND Institute and UC Davis Children’s Hospital, has been announced as a 2014 Rare Champion of Hope honoree in science. The honor, awarded by the Global Genes Project, recognizes her unwavering commitment to understanding rare diseases, her investment in new treatments and her care and respect for patients.

Rauen is an internationally respected leader in studying the Ras/MAPK pathway genetic syndromes, and coined the term “RASopathies.” Ras/MAPK regulates cell growth, which is critical for normal fetal development and, when dysregulated, can cause cancer. She opened the UC Davis NF/Ras Clinic last month.

New study examines autism in girls

Autism is far more common in boys than girls – affecting 1 in 54 boys and 1 in 252 girls – but little is known about biological differences between boys and girls with autism. A new study, called the ‘Girls with Autism – Imaging of Neurodevelopment’ or GAIN Study, led by researchers at the UC Davis MIND Institute will explore those differences in very young girls with autism.

Little is known about autism in girls. “We know that the incidence of autism is much lower in girls than it is in boys. But we don’t know much about why that is, and what those differences are,” said Christine Wu Nordahl, assistant professor of psychiatry and behavioral sciences and principal investigator for the study.

MIND Institute researchers are seeking girls with autism and girls developing typically – between the ages of 2 and 3.5 years old.

For further information about the research or to inquire about enrolling a child in the study, please contact Michelle Huynh, study coordinator, at 916-703-0410, or michelle.huynh@ucdmc.ucdavis.edu.

Generous gift to 22Q program

For Jennifer and Paul Quilkey, giving to the UC Davis MIND Institute’s chromosome 22q11.2 deletion syndrome program, led by Professor of Psychiatry and Behavioral Sciences Tony Simon, was an easy choice to make.

The Quilkeys were first introduced to Simon during a conference on 22q11.2 deletion syndrome. They were so impressed that they decided to visit the institute with their daughter, Emma, who had been diagnosed with the condition when she was 14.

While Emma received an evaluation, the entire family received a tour of the MIND Institute. Later another daughter, Ashley, spent time with Simon exploring her interest in a career in medicine.

“We just really enjoyed them,” Jennifer Quilkey said of Simon and other members of the faculty and staff of the MIND Institute. “They were very helpful to us in many different ways. So, I told my husband that, for my 50th birthday, I wanted to make a gift to the MIND Institute.”

Simon, who directs the MIND Institute’s Cognitive Analysis and Brain Imaging Laboratory (CABIL), said the Quilkey’s gift is a lifeline for children with 22q11.2 deletion syndrome and other similar conditions.

“This gift secures the immediate future of our 22q Healthy Minds Clinic, which allows us to translate our research findings into evidence-based clinical practice and specific action plans that help parents minimize their affected children’s intellectual, behavioral and mental-health issues,” Simon said.

“I have been working on that for a very long time,” he said. “Another family’s gift finally enabled me to get a really professional prototype built, but this new, very generous, gift from the Quilkey family will help me take that to a whole new level! This is very big, as it could be an important new way that we improve the lives of children with 22q and those of their families.”
MIND Institute hosts University of California Autism Summit

This summer marked an exciting milestone in the history of the MIND Institute – and that of autism research in California. On August 14, scientists from throughout the University of California came together at the MIND Institute to map out strategies for research and treatment collaboration across its health system campuses at the first-ever University of California Summit on Translational Research in Autism Spectrum Disorder. Sponsored by the UC Office of the President, the Summit was attended by more than 40 researchers and other guests of the world’s leading autism investigators from campuses at Davis, Irvine, Los Angeles, San Diego and San Francisco. The Summit was the first step in an 18-month process aimed at accelerating progress toward new treatments. Next steps will include drafting a strategic plan for a coordinated approach to University of California autism research, which will include identifying research opportunities, increasing the number of multi-campus research grants and launching a series of public and statewide autism forums. National Institute of Mental Health Director Thomas Insel attended by videoconference and noted that the effort was an excellent model for coordinated statewide autism research. The MIND Institute was honored to host, organize and secure funding for this seminal event, to begin to harness the unique basic science and translational research capabilities of one of the world’s largest and most prestigious research institutions. Working together and on multiple fronts I am confident we will accelerate progress toward improving the lives of the children and families who inspire our work every day.

Leonard Abbeduto
Director, UC Davis MIND Institute

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.