Katherine A. 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 received the Presidential Early Career Award for Scientists and Engineers (PECASE) at a ceremony in Washington, D.C. White House Office of Science and Technology Policy Director John Holdren was the keynote speaker for the event, held in the U.S. Department of Agriculture's Jefferson Auditorium. Agency officials, friends and relatives of the 102 award recipients attended the event. Afterward the recipients were greeted at the White House by President Barack Obama, who thanked them for their outstanding achievements.

The Presidential Early Career Awards for Scientists and Engineers, established by President Clinton in 1996, are coordinated by the Office of Science and Technology Policy within the Executive Office of the President. Awardees are selected for their pursuit of innovative research at the frontiers of science and technology and their commitment to community service as demonstrated through scientific leadership.

Gail Goldstein Heyman and her husband, Lyons, first met Randi Hagerman at a meeting of the National Fragile X Foundation in the early 1990s. The mother of a son with fragile X syndrome who then was 9 years old, Heyman found Hagerman's understanding of fragile X stunning.

“After hearing Hagerman’s talk, I remember putting Scott to bed at night saying to myself 'Now I know who you are!'” Heyman recalled. “Prior to that, I didn’t understand any of my son's anxieties or his social and cognitive behaviors. I didn’t understand what made him tick. I didn’t understand what his needs were or how to calm him.”

Fragile X would leave a lasting impression on the Heyman family, beyond their son’s diagnosis. Other family members also have been diagnosed with fragile X-related disorders: Heyman’s daughter Carly Heyman Godzanker was diagnosed with fragile X-primary ovarian insufficiency (FXPOI). Other family members have been diagnosed with fragile X-tremorataxia syndrome (FXTAS), a condition first identified by Randi and Paul Hagerman in 2003.
Randi Jenssen Hagerman, who has devoted her life to relieving the suffering of children and families affected by fragile X syndrome and related conditions worldwide through patient care, research and teaching, has received the Distinguished Scholarly Public Service Award from the UC Davis Academic Senate.

The medical director of the UC Davis MIND Institute, Hagerman is one of the world’s leading investigators into the disorders that include fragile X syndrome, the most common heritable cause of intellectual disability and single-gene cause of autism. She has lobbied the United States Congress to increase funding for fragile X research and is a founder of the National Fragile X Foundation.

Fragile X-related disorders include fragile X syndrome and fragile X-associated tremor/ataxia syndrome (FXGAS). Hagerman treats patients with these conditions from throughout the country and the world, and is an active and vocal champion for greater funding for research and treatment. She has established clinics and mentored physicians and researchers on virtually every continent. Hagerman currently is establishing a treatment site at a fragile X hotspot in Colombia.

“We’re forging relationships and developing diagnostic and treatment studies with many centers internationally to advance therapies for the tens of thousands of people who suffer from fragile X disorders worldwide,” Hagerman said. “We want families everywhere to benefit from the MIND Institute’s remarkable neurodevelopmental expertise in both fragile X and in autism.”

The award from the Academic Senate was announced April 29 and presented in a ceremony on May 13.

“I am humbled by this award and truly grateful for the recognition of the UC Davis Academic Senate for our international efforts in fragile X diagnosis and treatment,” Hagerman said. “My efforts represent a multidisciplinary team of wonderful clinicians and scientists who make our fragile X work truly outstanding and dramatically helpful for the patients and the families that we serve.”

Randi Hagerman receives Distinguished Scholarly Public Service Award

The child whose behavior first was illuminated by Randi Hagerman’s insights now is 33 years old. He lives independently with support with two of his best friends, has a job at Publix market and has won numerous medals in the Special Olympics, including medals in golf, tennis and power lifting. He inspired his little sister Carly to write a book: “My Extra Special Brother: How to Love, Understand and Celebrate Your Sibling with Special Needs.”

Finally, Carly’s diagnosis with FXPOI would inspire another sibling, Jared, to found CrowdMed, a San Francisco-based and venture-backed Silicon Valley startup which today harnesses the “wisdom of crowds” to help solve the world’s most difficult medical cases.

“(Randi Hagerman) has a way of connecting to exactly what your greatest needs and concerns are. She offers solutions and suggestions, and you’re always left better and stronger for having talked with her.”

– GAIL HEYMAN, cofounder of the Fragile X Association of Georgia

Gail Heyman is the co-founder of the Fragile X Association of Georgia, of which she is the president. Last year, she joined the UC Davis MIND Institute’s National Council of Visitors, to support the MIND Institute’s mission of advancing research into the causes of and treatments for neurodevelopmental disabilities.

“Randi Hagerman works closely with families in all of these areas, and her advancements on the clinical side are something that we want to support,” Heyman said. “There’s nothing like Randi Hagerman,” she said. “She has a way of connecting to exactly what your greatest needs and concerns are. She offers solutions and suggestions, and you’re always left better and stronger for having talked with her. She has fortified our family. She’s better than vitamin D!”

“(Randi Hagerman) has a way of connecting to exactly what your greatest needs and concerns are. She offers solutions and suggestions, and you’re always left better and stronger for having talked with her.”

– GAIL HEYMAN, cofounder of the Fragile X Association of Georgia
MIND Institute celebrates “22q at the Zoo!” Worldwide Awareness Day

The UC Davis MIND Institute on May 18 participated in 22q at the Zoo Worldwide Awareness Day to increase knowledge of chromosome 22q11.2 deletion/duplication syndrome. However, this time the zoo came to the MIND Institute, which hosted 20 families of children with the genetic disorder. The event was organized by the MIND Institute 22q11.2 Research and Clinical Center, directed by Professor of Psychiatry and Behavioral Sciences Tony J. Simon.

“Every year we are thrilled to host our family meeting, where we get to share our newest understanding of 22q11.2 with the families, learn from them and have them inform and help each other,” Simon said.

“There is always a really fun kids camp for all ages where the kids get to play and allow their parents to fully participate in the meeting. This year, Carrie Heran, one of our strongest supporters, advocates and parents, had the idea of combining 22q at the Zoo with our meeting, and I think it brought the best of both events together,” he said.

The day’s events were mirrored in 22q Worldwide Awareness Day activities throughout the globe, spearheaded by the International 22q11.2 Foundation, Inc. In addition to the zoo visitors, the MIND Institute event featured activities for children such as face painting and seminars for their parents.

Chromosome 22q.11.2 deletion syndrome is a congenital defect that affects at least 1 in 4,000 live births, 1 in 68 children with congenital heart disease and 5 to 8 percent of children born with cleft palate. Individuals with the disorder can also experience feeding, swallowing and breathing problems, learning disabilities, hearing loss, and cognitive and speech delays.

To learn more about chromosome 22q11.2 deletion syndrome, visit the UC Davis MIND Institute Cognitive Analysis and Brain Imaging Laboratory (CABIL) website or send an e-mail to cabil@ucdmc.ucdavis.edu
Annual Summer Institute on Neurodevelopmental Disorders

The UC Davis MIND Institute holds the annual Summer Institute on Neurodevelopmental Disorders: Research to Practice, on Friday, Aug. 8, from 8:30 a.m. to 5 p.m. at the UC Davis Alumni Center. The daylong conference offers nine seminars on a broad array of subjects delivered by some of the world’s leading experts on neurodevelopmental disorders.

“This conference will include valuable information for everyone who touches the lives of people with neurodevelopmental disabilities.”

– ROBIN HANSEN, CEDD director and conference chair

The Institute is intended for a wide range of professionals, including educators, psychologists, physicians, nurses, occupational therapists, physical therapists and speech and language pathologists, as well as families, caregivers and students. Presenters will address the latest advances in neurodevelopmental research and the most current standards for best practices in prevention, assessment, treatment and supportive services across the lifespan.

“This conference will include valuable information for everyone who touches the lives of people with neurodevelopmental disabilities,” said Robin Hansen, CEDD director and conference chair.

A series of workshops on evidence-based interventions will follow, as well as exhibits from community and advocacy organizations, businesses owned and operated by people with disabilities, and assistive technology devices. Friday’s events will be held at the UC Davis Buehler Alumni Center, 530 Alumni Lane, Davis, Calif., and the adjacent Conference Center.

Three pre- and post-conference workshops will be held at the MIND Institute in Sacramento, 2825 50th St. Internationally respected Distinguished Professor of Psychiatry and Behavioral Sciences Sally Rogers, developer of the Early Start Denver Model (ESDM) for autism early intervention, will hold an Introductory Workshop on ESDM during a pre-conference event on Thursday, Aug. 7. Post-conference workshops include a training update on the Autism Diagnostic Observation Schedule (ADOS – 2) Toddler Module on Saturday, Aug. 9, and an ESDM Advanced Workshop Aug. 11–13.

For the Aug. 8 conference, the tuition for health-care and other professionals is $195; groups of five or more professionals from the same agency who register together qualify for a group rate of $180 per person. Tuition for students, parents or caregivers is $115; the rate for two parents or caregivers registering together is $175. Early registration is recommended, as registration fees will increase after July 14. To register or to learn more, call 916-703-0268 or email ddcenter@ucdavis.edu.

Registration for the pre- and post-conference workshops is separate from registration for the summer institute. For information about prerequisites, fees and registration for the workshops, email esdmtraining@ucdavis.edu or call 916-703-0465.

The event is sponsored by the Center for Excellence in Developmental Disabilities (CEDD) at the UC Davis MIND Institute, UC Davis Health System and the Office of Continuing Medical Education.

Summer Institute on Neurodevelopmental Disorders:
Research to Practice
Friday, Aug. 8
8:30 a.m. to 5 p.m.
UC Davis Alumni Center
Register: ddcenter@ucdavis.edu
More information available at ddcenter@ucdmc.ucdavis.edu or 916-703-0268

Pre-conference workshop
Introductory Workshop on ESDM
Thursday, Aug. 7

Post-conference workshops
Autism Diagnostic Observation Schedule
Saturday, Aug. 9
ESDM Advanced Workshop
Mon–Wed, Aug. 11–13
MIND Institute
2825 50th St., Sacramento
Register: esdmtraining@ucdavis.edu
More information on pre- and post-conference workshops available at esdmtraining@ucdmc.ucdavis.edu or 916-703-0465.
Van de Water receives award to develop preventive treatment for autism

Judy A. Van de Water, a rheumatologist and professor of internal medicine in the UC Davis School of Medicine, is one of 11 scientists selected to receive an Individual Biomedical Research Award for 2013 from The Hartwell Foundation. The awards recognize early stage, innovative and leading-edge biomedical research with the potential to benefit children in the United States.

Van de Water is an autism researcher affiliated with the UC Davis MIND Institute. She is the eighth UC Davis researcher selected for the honor since 2008. Awardees receive $100,000 each year for three years, as well as videoconferencing equipment for periodic communications with the foundation and other award recipients.

In 2013, Van de Water described how unique antibodies in the bloodstreams of some pregnant mothers target proteins critical to the development of the fetal brain. If proven conclusive, the discovery represents the first definitive cause for a subset of cases of autism spectrum disorder (ASD). Van de Water coined the term Maternal Autoantibody-Related (MAR) autism to describe the 23 percent of autism cases associated with maternal autoantibodies.

“The Hartwell Foundation seeks to inspire innovation and achievement by offering individual researchers an opportunity to realize their professional goals.”

– FRED DOMBROSE, President of the Hartwell Foundation

The award will support her research to prevent the antibodies from affecting the developing fetal brain, by developing MAR antibody blocking peptides that could be administered to pregnant women. Such a treatment could eliminate nearly a quarter of future autism cases and save an estimated $29 billion per year related to caring for people with autism, according to Van de Water.

“The availability of a therapy to prevent MAR autism will potentially reduce the prevalence of ASD among U.S. children, improving the quality of life for children who would have been affected, as well as their families, while reducing the societal cost currently incurred through autism therapies,” Van de Water said.

In addition to the individual award, The Hartwell Foundation designated UC Davis as one of the Top Ten Centers for Biomedical Research in the country for the fourth consecutive year.

“The Hartwell Foundation seeks to inspire innovation and achievement by offering individual researchers an opportunity to realize their professional goals. We believe that philanthropy is a serious responsibility and that wealth appropriately used is an essential mechanism for improving the state of mankind,” said Fred Dombrose, president of The Hartwell Foundation.

“Through a unique and selective funding process, we provide financial support to stimulate discovery in early-stage biomedical research that we hope will benefit children of the United States. UC Davis has been a key partner with the foundation in accomplishing this goal.”

Rauen Continued from front page

public education or community outreach.

PECASE award recipients are selected from among individuals who either are funded or employed by federal departments and agencies. The National Institutes of Health honored Rauen for her studies on the role of germline mutations in the Ras/mitogen-activated protein kinase pathway on skeletal myogenesis. She is one of 35 awardees acknowledged through their association with the U.S. Department of Health and Human Services and one of the 20 National Institutes of Health honorees. She is one of only eight recipients in the University of California system.

Rauen is an internationally respected leader in the study of 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 earned her master’s degree in human physiology and her doctorate in genetics at UC Davis. She earned her medical degree at UC Irvine and completed residency training in pediatrics and a fellowship in medical genetics at UC San Francisco.
As the academic year ends, we remember that one of the most important roles of institutions like UC Davis is training the next generation of clinicians and researchers, and that is no less true of the MIND Institute. The MIND Institute continues to produce some of the finest and brightest new researchers in the field of neurodevelopmental research. Philanthropic support is vital to the tireless work of our early career faculty by providing crucial funding to help launch their pioneering research of autism and other neurodevelopmental disorders.

This past year, we used philanthropic support to launch an annual competition to support promising scientists from around the UC Davis campus. We created a rigorous review process that involved senior MIND Institute scientists as well as leading scientists from around the U.S. There was intense competition, with many outstanding proposals submitted. We were able to fund four projects, each of which has the potential to make a significant impact on our understanding and treatment of neurodevelopmental disorders. Dr. Melissa Bauman will be developing rodent models to understand the ways in which illnesses during pregnancy may affect risk for autism and other neurodevelopmental disorders. Dr. Veronica Martinez Cerdeño will be investigating specific mechanisms by which maternal autoimmunity adversely affects prenatal brain development and increases the risk of autism. Dr. Andrea Schneider will explore specific brain responses that will help document improvements in clinical trials involving individuals with fragile X syndrome and other disorders. Dr. Rebecca Schmidt will continue her notable early research on the importance of perinatal nutrition and genetic factors and autism risk.

Although these four outstanding scientists are early in their careers, they and others like them already are making remarkable contributions to our understanding of autism and other neurodevelopmental disorders. I am very proud that we are at the leading edge of training these and many other talented researchers who are committed to finding treatments and cures for the children and families we are privileged to serve. Your generous support continues to make this work possible. Thank You!

Leonard Abbeduto  
Director, UC Davis MIND Institute