



Inside the Institute
Newsletter for the Carolina Institute for Developmental Disabilities

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**Congratulations to Kenneth Kelty,
Recipient of the Laura Lee Self-Advocate Leadership Award**



Left to Right: Deb Zuver, CIDD Education Consultant; Jackie Kelty, Family advocate and Mr. Kelty's mother; Kenneth Kelty; Cate Weir, Coordinator Think College National Coordinating Center; Kelly Kelley, Director University Participant program at Western Carolina University (who received the Inclusive Higher Education Leadership Award)

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UNC Leadership Education in Neurodevelopmental Disorders (LEND) Trainee in Advocacy, Kenneth Kelty, is the recipient of the Laura Lee Self-Advocate Leadership Award. The Laura Lee Self-Advocate Leadership Award is given to a trailblazer who currently attends or has graduated within the last five years from a postsecondary education program for persons with intellectual or developmental disabilities. The award was presented at the 2017 State of the Art Conference on Postsecondary Education and Individuals with Intellectual Disabilities held on November 15-16 at Syracuse University, New York.

After graduating from Western Carolina University's University Participant program, Mr. Kelty was recruited by the Carolina Institute for Developmental Disabilities (CIDD) LEND program as a trainee in the discipline of Advocacy for the 2015-2016 academic year and was the first Inclusive Postsecondary Education (IPSE) graduate in North Carolina to participate in a graduate-level opportunity. During his time as a LEND trainee, Mr. Kelty served an active role in Project STIR (Steps Toward Independence and Responsibility), participating in a range of community-based training and technical assistance related to self-advocacy, self-determination, and inclusion, including advocacy training for high school students in Chapel Hill. He has taught classes on disability history, lectured at regional and national conferences, and has written many articles about his life with autism and inclusion on a college campus. He has also spoken to legislators in Washington, D.C., on the importance of access to higher education and the funding of model demonstration projects.

Mr. Kelty is actively involved in the North Carolina Postsecondary Education Alliance (NC PSEA), a diverse stakeholder group based at the CIDD that focuses on expanding inclusive higher education across North Carolina. He is part of the effort to launch NC Empowerment Network, a new NC self-advocacy group and is a member of CIDD's Consumer Advisory Committee. CIDD also recruited Mr. Kelty to participate in further leadership training this current academic year through the MCH Leadership Consortium. He continues to find new opportunities to share stories and perspectives, incorporating his sense of humor and positivity to engage audiences—whether in person or through his blogs and articles. He reaches a range of audiences—students, families, professionals—and consistently steps up to new opportunities to share information and experiences about the positive impact of inclusion and self-determination.

The Laura Lee Self-Advocate Leadership Award is named in memory of Laura Lee, daughter of Gen and Stephanie Smith Lee, who was a pioneer in inclusive education at the national level. She passed away unexpectedly in 2016.

CIDD Director of Research Dr. Gabriel Dichter receives the 2017 Junior Faculty Mentor of the Year Award from the UNC Department of Psychiatry



Dr. Bradley Gaynes (left), Professor of Psychiatry and Associate Chair of Research Training and Education, presents the 2017 Junior Faculty Mentor of the Year Award from the UNC Department of Psychiatry to Dr. Gabriel Dichter (right).

The UNC-Chapel Hill Department of Psychiatry awarded CIDD Director of Research Dr. Gabriel Dichter with the 2017 Junior Faculty Mentor of the Year Award. This award was established by the department to recognize the commitment of faculty members to the career development specifically of junior faculty.

Dr. Dichter's commitment to junior faculty mentoring includes serving as primary mentor or co-mentor to a number of K-awardees in the Department of Psychiatry, including currently the KL2 award of Dr. Erin Walsh, UNC Assistant Professor of Psychiatry, who is studying linkages between inflammation and neural responses to rewards in anhedonic patients, and Dr. Crystal Schiller, UNC Assistant Professor of Psychiatry, who is studying the effects of estradiol on neural responses to rewards in perimenopausal depression.

Dr. Dichter has also mentored many CIDD postdoctoral fellows who were supported by the CIDD T32-funded postdoctoral training program in neurodevelopmental disorders, including currently Dr. Jessica Kinard, who is learning methods to probe striatal dopaminergic responses to rewards in autism using simultaneous PET/MR, and previously Dr. John Richey, who is currently Associate Professor of Psychology at Virginia Tech.

Dr. Dichter is also NC LEND faculty and is currently mentoring the research projects of LEND trainees Alissa Hopper (Department of Allied Health Sciences) and Dianna Padilla (MPH Graduate Student). Finally, Dr. Dichter has been primary mentor to multiple clinical psychology, developmental psychology, and school psychology doctoral students, including currently Maya Mosner, who is studying the neural mechanisms of reward learning in autism, Rachel Greene, who is studying neural responses to acute intranasal oxytocin in autism, and Paul Cernasov, who is learning experimental therapeutic approaches to evaluating novel anhedonia treatments using high-field functional neuroimaging.

Shoba Sreenath Meera Joins CIDD on Fulbright-Nehru Postdoctoral Research Fellowship

Shoba Sreenath Meera, PhD, joined the CIDD in August 2017 on the coveted Fulbright-Nehru post-doctoral fellowship. Dr. Meera is a speech-language pathologist from Bangalore, India. She obtained a PhD for her work on pragmatic language abilities in the broad autism phenotype from the National Institute of Mental Health and Neurosciences (NIMHANS) in Bangalore. Her clinical and research interests include early detection and intervention in children with developmental disorders, co-morbidity in autism spectrum disorder (ASD), and understanding social communication difficulties in siblings of children with ASD.



During her two-year stint here at CIDD, Dr. Meera will be mentored by Dr. Joe Piven. She will be studying language markers such as canonical babbling during infancy, and examining whether it can predict later diagnosis of autism and related language disorders in high-risk infants. "It is wonderful to have this opportunity to work with Meera," says Piven. "She and I have worked together for several years and have published together. We are thrilled that she is able to join our lab for the next two years."

Pictured are members of the Piven Lab. Standing left to right: Shannon Sweeny, Shoba Meera, Heather Hazlett, Heidi McNeilly, Rachel Smith, Michael Graves. Sitting left to right: Joe Piven, Leigh Anne Weisenfeld, Mark Shen, Meghan Swanson.

UNC Named NIH Autism Center of Excellence



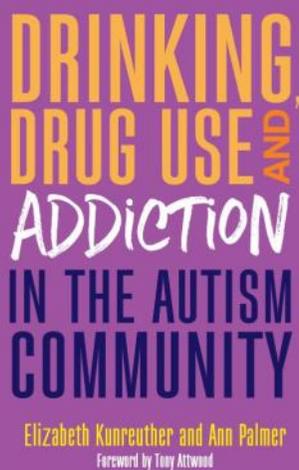
The National Institutes of Health has awarded nine research grants totaling nearly \$100 million over the next five years for the Autism Centers of Excellence (ACE), a program that supports large research projects aimed at understanding and developing interventions for autism spectrum disorder. The ACE program was created in 2007 from the consolidation of previous programs. Grants have been awarded every five years, and 2017 marks the third cycle of ACE grants. UNC-Chapel Hill is one of only two lead sites to have earned grants in all three cycles, in addition to having been awarded a Center grant under the previous mechanism in 2002, the NIH Studies to Advance Autism Research and Treatment (STAART) Centers.

Led by Joseph Piven, MD, the Thomas E. Castelloe Distinguished Professor of Psychiatry in the UNC School of Medicine and director of the Carolina Institute for Developmental Disabilities, the UNC team and colleagues from Children's Hospital of Philadelphia (CHOP), University of Washington, Washington University of St Louis, McGill University, Johns Hopkins University, University of Minnesota, University of Alberta, and New York University previously compiled detailed information on brain development and behavior for hundreds of infants at high familial risk for autism and 100 infants at low risk. The researchers found that the rate of brain growth of infants later diagnosed with autism differed from that of typically developing children. Piven's network also discovered key differences in brain connections to predict which infants will develop autism. A third study led by UNC researchers showed that increased infant cerebral spinal fluid is linked to autism diagnoses at age two.

With the new award – \$1.5 million per year over five years – the Infant Brain Imaging Study (IBIS) Network will follow these children through 7 to 10 years of age to determine how their brains change as they grow and how these changes relate to other manifestations of autism risk at school age, including learning problems, other psychiatric disorders, and social development, as well as whether early brain markers can predict the occurrence of these and related problems. They will add data from these studies to longitudinal brain and behavior data from earlier development in these children, as well as extensive genetic and environmental exposure data. The researchers will then use their findings to examine ways to conceptualize new subcategories of autism that are more closely related to underlying biology and may provide a more specific approach to treatment.

"Autism spectrum disorder has myriad environmental, genetic, neurological and behavioral components," said Diana W. Bianchi, MD, director of NIH's Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), 1 of 5 institutes funding the ACE program. "These awards will allow us to understand how autism differs in girls versus boys, to develop earlier methods of screening, and to improve treatments based on specific symptoms."

The NICHD and the National Institute of Environmental Health Sciences (NIEHS) are funding the UNC ACE award.



New Book Explores Drinking, Drug Use, and Addiction in the Autism Community

What is the connection between autism and addiction? Why are individuals with autism more likely to develop a substance use disorder than the general population? Until recently, substance use disorder (SUD) was considered rare among those with autism spectrum disorder (ASD), but recent research on this topic suggests that individuals with autism are nearly twice as likely to develop SUD.

DRINKING, DRUG USE AND ADDICTION IN THE AUTISM COMMUNITY, a new book written by Ann Palmer and Elizabeth Kunreuther, published by Jessica Kingsley Publishers (October 19, 2017), brings together current research and personal accounts from individuals with autism and their supports. The book explores why addiction is more common among individuals with ASD, investigates how addiction and autism affect one another, and provides strategies for supporting people with both ASD and SUD.

Ann Palmer is the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Family Faculty at the CIDD who has worked in the disabilities field for 25 years. Elizabeth Kunreuther is a clinical instructor at the University of North Carolina's WakeBrook Detox and Addiction Unit. She is a LEND Family Fellow and graduate of the MSW program at UNC.

UNC Football Family Embraces Fight Against Pitt-Hopkins Syndrome



On Saturday, October 7, at the start of the UNC home football game against Notre Dame, five-year-old Logan Bomar was on the 50-yard line in Kenan Stadium with her parents for the coin toss, an honor bestowed on Logan as the UNC Children's Hospital Kids Champion. Logan was diagnosed with Pitt-Hopkins syndrome in November 2015.

Pitt-Hopkins syndrome is a rare neurological disorder caused by the loss of a single gene – TCF4. Still, Logan is just like any other girl her age. She has a beautiful smile, accompanied by a heartwarming giggle. She loves balloons and horses and music. And, on this day at the football game, her brown hair is pulled back in pigtails, flapping in the breeze as her parents, Brooke and David Bomar, lift her by the arms with each step they take toward midfield.

Logan can walk by herself, just a few steps at a time right now. Pitt-Hopkins syndrome is characterized by significant developmental delays, such as problems with motor coordination and balance. Breathing abnormalities and seizures are also common – Logan experiences neither. As is the case for most people with Pitt-Hopkins syndrome, Logan's biggest obstacle is communication. She currently doesn't talk. She expresses herself with her eyes and hand gestures, though, and could still develop a limited vocabulary.

Among the people standing on the Tar Heels' sideline Saturday was Dr. Ben Philpot, the Associate Director of the UNC Neuroscience Center and member of the Carolina Institute for Developmental Disabilities (CIDD). The Bomars first contacted Philpot, who started studying Pitt-Hopkins syndrome about five years ago, shortly after Logan's diagnosis. Within a few weeks, the family was touring his lab and discussing his team's findings. That marked the first of what have become fairly regular meetings. "Just being able to meet Logan and her wonderful family," Philpot said, "it's great inspiration for me. It allows me to take that as motivation back into the lab."

There are two broad approaches for treating Pitt-Hopkins syndrome: either to fix the secondary neurological deficits caused by the loss of TCF4, or to directly reinstate normal TCF4 gene expression. The Philpot lab is taking both of these approaches in parallel. In one line of research, the Philpot lab is identifying how neurotransmission in the brain is disrupted by the loss of TCF4 so we can design logical drug treatments to normalize neurotransmission. In another line of research in collaboration with Dr. Steve Gray, who is a world leader in gene therapy, the Philpot lab is testing the extent to which gene reinstatement of TCF4 can safely correct behavioral deficits associated with Pitt-Hopkins syndrome. The ultimate goal of both these strategies is to improve the lives of individuals with Pitt-Hopkins syndrome.

Logan's family is on a mission to spread awareness about Pitt-Hopkins Syndrome and raise funds for research for a cure. All donations made to the [Pitt Hopkins Research Foundation](http://PittHopkinsResearchFoundation.org) in honor of Logan will be used to fund CIDD research into finding a cure for Pitt Hopkins. Read full story at GoHeels.com

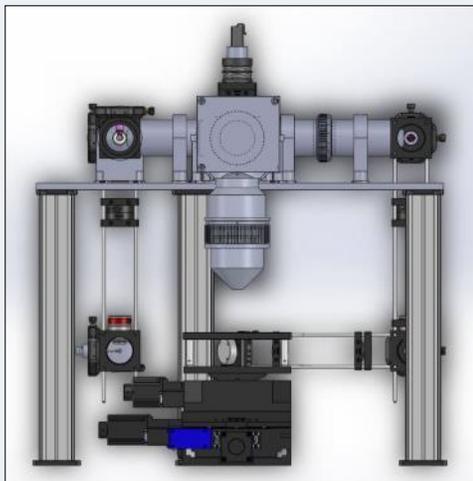


Logan and her family with Ben Philpot (pictured far right) at the UNC Football game.

CIDD Investigator to Lead \$10-Million Project to Build Brain-Imaging Technology

The brain is so incredibly important to human health and yet so little is known about how it works. MRIs and other kinds of scans can reveal important things about brain health in broad strokes to aid in diagnostics, but they aren't able to uncover important details of brain function, such as how neurons talk to each other. This is where Spencer Smith, PhD, and his lab at the UNC School of Medicine come in.

Smith, an Associate Professor of Cell Biology and Physiology and member of the UNC Neuroscience Center and Carolina Institute for Developmental Disabilities, is a world expert in developing multiphoton imaging systems – an evolution of the standard microscope – and using them to observe brain activity in much greater resolution than MRIs, [down to individual brain cells](#).



3D rendering of a next-generation multi-photon neuroimaging system built in the Smith lab at UNC. There are two independent scan engines coupled into a single objective for simultaneously imaging two different brain areas.

To help further Smith's work, the National Science Foundation (NSF) awarded him \$10 million over five years. He will lead a consortium, including his lab and eight other scientific teams across the country. This is part of the NSF's new NeuroNex Awards, which bring together researchers from across various disciplines to create new technologies and explore the mysteries of the brain like never before. By the end of five years, the NSF hopes to have established a national infrastructure to enhance our understanding of brain function.

"This is an ambitious project I'm excited to be part of," Smith said. "Our goal is to create the next generation of multi-photon neuroimaging technology to provide unprecedented views into brain activity with the goal of learning as much as possible about how the brain works in health and disease."

Smith's project can be summarized in three parts:

- Develop imaging systems to make currently impossible neuroscience experiments possible.
- Disseminate multi-photon neuroimaging technology through open source and commercial enterprises to allow a broad community of neuroscientists to take advantage of the new technology for new research projects.
- Advance the basic physics and engineering technology to lay the groundwork for future neuroimaging technologies.

Multi-photon imaging – usually two-photon or three-photon – uses a quantum mechanical effect to see deep into the brain relatively non-invasively. The imaging systems use bursts of light so intense that the cellular molecules absorbing the light can't tell where one photon ends in the beam of light and the next photon begins. This is crucial because brain tissue is like a bramble of intertwined cells that conventional microscopes can't penetrate. Looking through a conventional one-photon microscope, only blurry images can be seen.

Multi-photon imaging systems use lower energy photons that scatter less in the brain so that researchers can see a particular image deeper. Multi-photon absorption occurs only at high intensities right at the focal point to limit background clutter. The result is a much clearer image into deep tissue to reveal the structure of tiny things.

Smith though, is taking this process a step further. His goal is to view these tiny structures in a field of view so wide that he can see over a million neurons, across multiple brain areas, at incredibly high resolution. But to see such tiny structures in a large field of view, [Smith's team had to custom design the imaging systems](#), build the systems themselves, and then have the experimental know-how to test them. He has built prototypes at UNC and used them experimentally since joining the UNC School of Medicine in 2013.

"We want to create the next generation of multiphoton imaging to enable neuroscientists to explore the brain in new ways, making previously impossible experiments possible," Smith said. "This technology is critical for basic, fundamental brain science, as well as understanding disease processes and potential therapies."

Check the [Next Generation Multiphoton Neuroimaging Consortium website](#) for more information.



Dr. Spencer Smith building a two-photon imaging system at UNC.

Dr. Cynthia Powell Appointed to U.S. Department of Health and Human Services Advisory Committee on Heritable Disorders in Newborns and Children



Cynthia Powell, MD, Professor of Pediatrics and Genetics and LEND faculty member, has been appointed to the U.S. Department of Health and Human Services (DHHS) Advisory Committee on Heritable Disorders in Newborns and Children. The mission of the Advisory Committee is to reduce morbidity and mortality in newborns and children who have, or are at risk for, heritable disorders. The Committee advises the Secretary, U.S. DHHS on the most appropriate application of universal newborn screening tests, technologies, policies, guidelines, and standards including which conditions should be added to the Recommended Uniform Screening Panel (RUSP).

The Advisory Committee on Heritable Disorders in Newborns and Children recommends that every state newborn screening program include a Uniform Screening Panel that screens for 34 core disorders and 26 secondary disorders. The Committee utilizes evidence-based reviews of conditions that are nominated to the RUSP that include the potential net benefit of screening, the ability of states to screen for the disorder, and the availability of effective treatments. In addition, the Committee provides to the Secretary, the following:

- Advice and recommendations concerning grants and projects authorized awarded or funded related to screening heritable disorders in newborns and children.
- Technical information to develop Heritable Disorders Program policies and priorities that will enhance the ability of the state and local health agencies to provide screening, counseling and health care services for newborns and children who have or are at risk for heritable disorders.
- Recommendations, advice and information to enhance, expand, or improve the ability of the Secretary to reduce mortality and morbidity from heritable disorders in newborns and children.

Garret Stuber Named Co-Recipient of the Waletzky Award



Garret Stuber, Ph.D., Associate Professor of Psychiatry and Cell Biology and Physiology in the UNC School of Medicine and a member of the UNC Neuroscience Center and Carolina Institute for Developmental Disabilities, has been named a co-recipient of the Jacob P. Waletzky Award, which is given by the Society for Neuroscience.

Supported by the Waletzky Award Prize Fund and the Waletzky Family, this \$25,000 award recognizes young scientists who have conducted or plan to conduct independent research leading to significant conceptual and empirical contributions to the understanding of drug addiction. Scientists eligible for this award must have conducted or an established plan to conduct independent research within 15 years of receiving their PhD or MD degree.

The award will be presented at Neuroscience 2017, SfN's annual meeting and the world's largest source of emerging news about brain science and health. The other co-recipient is Karen Ersche, PhD, of Cambridge University in England.

"It is important to recognize the work of scientists combatting the global crisis of drug addiction," SfN President Eric Nestler said. "We could not have two candidates more deserving of this year's Waletzky Award than Karen Ersche and Garret Stuber, who have illumined new approaches to treatment and a more foundational understanding of how drug addiction affects the brain, respectively."

In the seven years since Stuber started his lab, he has become internationally known for his work characterizing neural circuits underlying behaviors associated with addiction, depression, and eating disorders.

Stuber, who was named a [Yang Family Biomedical Scholar](#) in 2016, has contributed to knowledge of specific circuits and neurotransmitters associated with addictive behaviors and of how drug abuse modulates neural coding dynamics. He pioneered cell-level resolution *in vivo* calcium imaging, and his addiction research has led to the development and use of optogenetic technologies and provided insight into how synaptic plasticity is involved in drug addiction.

Congratulations to Donna Carlson Yerby on Her Retirement

The CIDD is celebrating Donna Carlson Yerby, MEd, and her many years of accomplishments as she retires. Ms. Yerby is recognized for serving as Education Faculty and for her committed collaboration toward education reform. Ms. Yerby's guidance and encouragement has helped trainees thrive over the years. Her work with clinic teams is a testament to her competency and commitment to students and families. She is a strong believer in promoting leadership and was instrumental in recruiting trainees in self-advocacy, an innovative development at the CIDD.

As the national momentum grew to expand inclusive postsecondary education options for students with intellectual disability, Ms. Yerby was actively involved. She cofounded the NC Postsecondary Education Alliance, a stakeholder group that promotes inclusive higher education for students with intellectual disabilities and she has spoken locally and nationally about innovative NC models. Ms. Yerby was involved with related program evaluation projects and most recently she has been active with efforts to create an inclusive model at UNC that she named HEELS UP (Higher Education, Employment, Living Success-University Participant). While Ms. Yerby will be greatly missed, we wish her the best in her retirement.



Donna Yerby and Deb Zuver Receive CIDD IMPACT Award

Donna Yerby (pictured left) with Deb Zuver, MA (right), Director of Advocacy Initiatives and Project STIR (Steps Toward Independence and Responsibility), are recipients of the 2017 CIDD IMPACT Award. The CIDD Impact Award, established in 2016, recognizes the outstanding and lasting contribution of a professional, family member or self-advocate within the NC developmental disability community toward improving the quality of life for individuals and their families. Critical contributions to the field of IDD may be accomplished through innovative research, state-of-the-art interdisciplinary training/education, evidence-based clinical service, advocacy or policy and program development.

Ms. Yerby and Ms. Zuver received this award in recognition of their outstanding and critical contributions to postsecondary education opportunities at CIDD, in North Carolina, and nationally.

Welcome to Our Newest CIDD Faculty Members



Diana Cejas, MD, MPH, is a pediatric neurologist and Assistant Professor joining the CIDD faculty. She is a graduate of Howard Medical School, completing a residency in Pediatrics at Tulane University School of Medicine and fellowship in Child Neurology at the University of Chicago. In addition, Dr. Cejas was an Illinois LEND fellow from 2016-2017, receiving extensive training in the field of neurodevelopmental disabilities.



Laura Hiruma, PhD, is a psychologist and Clinical Assistant Professor at the CIDD. Dr. Hiruma completed her PhD in Clinical Psychology at the University at Albany. She completed pre-doctoral training through the LEND/UCEDD program at the University of Colorado School of Medicine and a postdoctoral fellowship through the LEND/UCEDD program at the CIDD. She has worked with individuals with autism and other neurodevelopmental differences over the past ten years in research, educational, home, and clinic settings.



Mark Shen, PhD, is a neuroscientist and newly appointed Assistant Professor at the CIDD and Dept. of Psychiatry. Dr. Shen completed his PhD in Cognitive Neuroscience at the UC Davis MIND Institute, and his postdoctoral fellowship in the T32 program at the CIDD. Prior to graduate school, he worked six years as a behavior therapist with individuals with autism. Dr. Shen was recently awarded an NIH-funded career -development grant (K12) to extend his research program on early biomarkers for autism, Fragile X, and Angelman syndrome.

UCEDD Grant Renewed to the CIDD for Five Years for \$2,735,000

The CIDD is home to the University Center for Excellence in Developmental Disabilities (UCEDD) in the state of North Carolina. Funded by the Administration for Intellectual and Developmental Disabilities and co-Directed by Drs. Joe Piven and Becky Pretzel, the NC UCEDD received an outstanding score and was renewed for five years of funding. This federal funding provides critically-important services to fulfill the mission of the CIDD and to build capacity in the state for services to individuals with developmental disabilities and their families. The NC UCEDD funding supports interdisciplinary clinical training to providers at all levels; supports basic and applied research, including evaluation of community and government services and public policy analysis; dissemination of key information to the community; direct service and technical assistance to the community, and works to build important programs throughout the state to assist individuals with intellectual and developmental disabilities.

The NC UCEDD program has been funded at UNC since the early 1960s and has been an integral part of the NC service system for persons with developmental disabilities in the state of North Carolina. In the past 5 years, the NC UCEDD, together with the other federally-funded programs of national significance (the Leadership Education in Neurodevelopmental Disorders Program, or LEND, and the NICHD-funded Intellectual and Developmental Disorders Research Center, or IDDRC) provided interdisciplinary preservice training to over 800 trainees; community education and training to approximately 20,000 participants; technical assistance to almost 19,000 individuals and agencies; and direct services to nearly 6000 persons with intellectual and developmental disabilities and their families.

The mission of UCEDDs, present in every state in the country, is to work collaboratively within each state's DD Network which includes North Carolina's Council on Developmental Disabilities and Disabilities Rights NC. Current efforts in the NC UCEDD provide training for healthcare professionals, promote postsecondary education opportunities for individuals with IDD throughout the state, and support a self-advocacy leadership program – together with our partners in the North Carolina Developmental Disabilities Network.

We are thrilled with this new funding and the opportunities it affords the CIDD to continue to support individuals and families throughout the state of North Carolina. Congratulations to the CIDD UCEDD faculty and staff for a job well done!



Join Us for the CIDD Community Talk Series!

The CIDD hosts a series of talks to share information about recent advances in developmental disabilities. All talks are free, and everyone is welcome. Time: 6:30 PM to 8:00 PM Where: CIDD Castelloe Conference Room 101

For more information or to RSVP, please contact Dr. Debbie Reinhartsen at Debbie.Reinhartsen@cidd.unc.edu or 919-966-4138.



Wednesday, December 6

Robert Schooley, LCSW

Behavior Specialist - Chatham County Schools
Certified Trainer - Nonviolent Crisis Intervention
Field Instructor - UNC School of Social Work
Faculty Advisor - Boston University School of Social Work

In this discussion, we will identify the signs/symptoms, dynamics, and effects of bullying. In addition, we will identify ways to address this issue.

Researchers Ramp Up New UNC Autism Research Center

Two labs at UNC — led by Drs. Mark Zylka and Ben Philpot — have conducted experiments showing how different chemicals, including fungicides, can affect genes linked to autism.

Epidemiologist Dr. Julie Daniels created a method to study early life exposure to flame retardants and pollutants, the largest epidemiological study in the world designed to compare children with autism and other developmental delays with people who do not have such delays.

Dr. Joseph Piven's group at the Carolina Institute for Developmental Disabilities (CIDD) published a wave of scientific papers showing it is possible to predict which high-familial risk infants will develop autism as toddlers. Piven also is one of few researchers in the country studying autism in older people.

Drs. Sam Odom's and Laura Klinger's labs are developing behavioral intervention programs for adolescents and young adults focused on improved quality of life in adulthood.



Growing up with his autistic brother Mason lead UNC student Austin Ludwig to the Carolina Institute for Developmental Disabilities and helped chart his academic course. (Photo by Anna Routh Barzin '07)

Carolina has long been one of the world's premier autism research universities, and now its expertise and diverse research programs are coming under one virtual roof at the [UNC Autism Research Center](#).

More than 100 faculty, students and postdoctoral researchers from 32 departments within five schools currently work on autism-related grants. All will fall under the banner of the new center to focus on autism at all stages of life.

"The research center holds great promise for building on our knowledge about biological causes of autism, the range of characteristics of individuals with autism, behavioral interventions to address development and learning needs, and the most effective interventions matched to the needs of individuals with autism," said Odom, who is co-chair of the center's executive committee and director of the Frank Porter Graham Child Development Institute.

While the center will be housed within the CIDD at the UNC School of Medicine, its researchers will span the University, working across all areas of autism research — genetics, development, biomedical and cognitive.

Zylka is director of the UNC Neuroscience Center; Philpot is associate director. Piven, co-chair of the new center's executive committee, is director of the CIDD. Daniels works in the Gillings School of Global Public Health. Klinger directs the UNC TEACCH Autism Program.

"This new center gives us the opportunity to work with basic scientists and clinical researchers on a much deeper level to pursue more targeted and effective interventions," Klinger said.

One in 68 children in the U.S. is diagnosed with autism spectrum disorder, which is characterized by a wide range of challenges related to communication, social skills and repetitive behaviors. North Carolina's autism rate is above the national average, with about 65,000 people diagnosed with the condition, which is more common in boys.

One path toward targeted treatments runs through the study of genetics. It could be that different autism symptoms are linked to different genetic subtypes. If so, then addressing underlying genetics might benefit people with autism. For this, basic scientists, clinical researchers, health care professionals and families must work together to figure out the best ways forward.

Research projects that cross traditional research boundaries don't typically get NIH funding. Zylka said the center will help researchers attract funding for innovative projects, foster new collaborations and ultimately help people with autism and their families.



Left to Right: Casey Okoniewski, Laura Hiruma, Ben Philpot, Anne Wheeler, Heather Hazlett, Margaret DeRamus, Michael Sidorov, Mark Chen, and Ellen Clark, attended the Angelman Syndrome Foundation Scientific Symposium and Conference in Phoenix, AZ, this July to present latest research and clinical activities occurring at UNC.

Benefits of Inclusive Leadership Training

An article that reviews the benefits of inclusive leadership training, *Reflections on the Contributions of Self-Advocates to an Interdisciplinary Leadership Development Program for Graduate Students in Health Affairs*, has been accepted for publication in *Disability and Health Journal*. This contribution to the field was submitted by a team that includes Lew Margolis, Head of the Master's Program for the UNC SPH Department of Maternal and Child Health and LEND Faculty; McCafferty, LEND Advocacy Faculty at the CIDD, and Deb Zuver, Education Consultant at the CIDD and facilitator of the NC Postsecondary Education Alliance.

Stephanie Fox Receives the Wallach Award



Stephanie Fox, PhD, currently a Psychology Post-Doctoral Fellow at the CIDD, is the recipient of the 2016-2017 Martin S. Wallach Award. The Wallach Award is given annually to an outstanding doctoral candidate in Clinical Psychology chosen by faculty of the APA-approved UNC Clinical Psychology Internship Program. Recipients of the Wallach Award must demonstrate superior competence, including excellence in research, clinical practice, teaching, and/or service endeavors.

Dr. Fox's roles at the CIDD include participating as part of interdisciplinary diagnostic and treatment teams, conducting individual psychotherapy with individuals with I/DD, and working as a clinician for the CDC-funded Study to Explore Early Development (SEED). Her clinical and research interests include differential diagnosis of intellectual/developmental disabilities, interdisciplinary diagnostic assessment, and family-focused interventions for individuals with autism spectrum disorder.

Welcome T32 Postdoctoral Trainees

The CIDD T32 Postgraduate Research Training Program develops researchers with expertise in both the biological basis and clinical manifestations of neurodevelopmental disorders. This broad-based and integrated perspective enables researchers to better relate across disciplines and maximizes the potential for major research advances in understanding the pathogenesis and treatment of these disorders.



Charles Shyng, PhD, received his bachelor of arts in biology-neuroscience and doctorate in molecular cell biology from Washington University in St. Louis. Working in the laboratory of Dr. Mark Sands at Washington University School of Medicine, Dr. Shyng studied lysosomal storage disorders, specifically Infantile Batten disease. For his dissertation, Dr. Shyng developed a murine model of Infantile Batten disease that allowed for conditional cell-specific expression of the deficient lysosomal enzyme in order to understand the pathogenic mechanisms of disease. In a collaborative effort, he identified spinal cord pathology in Infantile Batten disease and utilized adeno-associated viral (AAV) vector-based combinatorial strategies to target the diseased areas. As AAV-based gene therapy is moving towards becoming the gold standard for treatment of rare and orphan diseases, Dr. Shyng joined UNC to work with Dr. Steven Gray to gain experience in viral vector design for gene therapy research and to continue the study of rare and orphan neurologic disorders. His project focuses on the development of novel AAV vectors capable of enhanced and broad

transduction of central nervous system cell types. Concurrently, Dr. Shyng is being co-mentored by Dr. Ben Philpot with the goal of developing an AAV-based gene therapy approach to treat Angelman Syndrome.



Brianne Tomaszewski, PhD, MPH received her doctorate in Applied Developmental Science from Colorado State University in the Department of Human Development and Family Studies under the mentorship of Dr. Susan Hepburn and Dr. Deborah Fidler. Dr. Tomaszewski's research focuses on adaptive behavior and behavioral interventions for individuals with neurodevelopmental disorders across the lifespan, and how these interventions influence outcomes in adulthood, such as postsecondary education and employment. During her doctoral work, she implemented an adult postsecondary education program for adults with Down syndrome targeting adaptive behavior skills in collaboration with Dr. Karen Riley at the University of Denver. Her dissertation work examined adaptive behavior trajectories from toddlerhood to middle childhood in individuals with Autism Spectrum Disorder (ASD) and individuals Down syndrome. Dr. Tomaszewski joined the CIDD T32 program to work with Dr. Sam Odom at the Frank Porter Graham Child Development Institute to study the effects of a randomized-controlled trial of the Center for Secondary

Education for Students with Autism (CSESA), a comprehensive school and community-based intervention. Dr. Tomaszewski plans to study whether participation in the CSESA program compared to services as usual has a positive effect on adaptive behavior, social skills, and participation for students with ASD during high school and adulthood. Her research aims to increase our understanding of how targeted interventions may effectively promote optimal postsecondary outcomes in individuals with ASD and other neurodevelopmental disorders.



Justin Wolter, PhD, received his bachelor of science degree in psychology from Utah State University, where he studied learning and behavior using operant conditioning. For his graduate work at Arizona State University, Dr. Wolter became interested in evolutionary biology and molecular genetics, and pursued his PhD under the mentorship of Dr. Marco Mangone. Dr. Wolter's thesis work characterized the recent evolutionary expansion of a class of regulatory genes called microRNAs, and explored how the evolutionary patterns of microRNA expansions contributes to development and diseases such as cancer. For his post-doctoral work at UNC, Dr. Wolter is co-mentored by Drs. Mark Zylka and Jason Stein, where he applies his expertise in molecular and cellular biology with modern genetics to identify common genetic variants that influence regulatory pathways implicated in autism. The aim of his research is to better understand the molecular mechanisms underlying the autism spectrum, and perhaps provide a more causal explanation of how genetic variation contributes to autism risk.



Dr. Spencer Smith Awarded UNC Hettleman Prize

Spencer Smith, PhD, Associate Professor of Cell Biology and Physiology, has been awarded the Philip and Ruth Hettleman Prize for Artistic and Scholarly Achievement by Young Faculty for his work on understanding the roles of brain connections in human health.

Smith, who is also a member of the UNC Neuroscience Center and the Carolina Institute for Developmental Disabilities, leads a highly interdisciplinary research program that focuses on better understanding how parts of the brain work in concert to perceive stimuli, perform computations, and drive behavior. Smith's research is currently focused on the visual cortex, the part of the mammalian brain that solves sophisticated computational problems. The long-term goal of Smith's lab is to explain principles of brain function to identify potential therapeutic targets and strategies for treating complex neurological disorders.

Kathleen Caron, PhD, chair of the Department of Cell Biology and Physiology, said Smith is "one of our most creative, innovative, and groundbreaking scholars" who possesses dual talents as an inventor and critical thinker. [Smith designs and builds](#) new imaging systems to conduct experiments that have never before been attempted. "As an inventor, Dr. Smith has relied upon his training in mathematics and physics to develop new machines, microscopes, and lenses that permit the real-time visualization of actively firing neuronal circuits on a wide scale, and in some cases, even within two different areas of the visual cortex simultaneously," Caron said.

During the early phase of his independent career, Smith has also published 14 papers in such prestigious journals as *Nature*, *Nature Biotechnology*, *Nature Neuroscience*, *Neuron*, *Nature Neuron* and *Journal of Neuroscience*. Smith's creativity and innovation has resulted in several prestigious junior investigator awards and grants from the McKnight, Simons, Whitehall, and Klingenstein foundations, two from the Human Frontiers in Science Program, and two NSF BRAIN Initiative grants, including one this year for \$10 million to lead a national consortium of researchers to create new technologies to study the mysteries of the brain. (see story on page 1).

New Federally Funded Training Grant Will Prepare Future Clinicians to Work with Children Who Have Hearing Loss and Developmental Disabilities



An interdisciplinary team of clinicians and graduate students from the Hearing and Development Clinic at CIDD work with a child and his mother to conduct a communication assessment.

The Hearing and Development Clinic at CIDD will be a key partner with UNC's Division of Speech and Hearing Sciences, Department of Allied Health Sciences, in preparing 28 graduate students in audiology and speech-language pathology over the next four years to assess and treat children who have congenital hearing loss with autism or other developmental disabilities.

Project director Dr. Jack Roush, who also serves as director of NC LEND, will work with co-project directors Dr. Cara McComish and Dr. Melody Harrison from the Division of Speech and Hearing Sciences, to administer the new \$850k grant. Dr. Roush notes that "nearly 40% of children with congenital hearing loss have one or more additional challenges that include autism and other developmental disabilities."

We are grateful to the US Department of Education, Office of Special Education Programs, for making these grants available and we are pleased that the reviewers recognized the critical need for this specialized training at UNC." The Hearing and Development Clinic at CIDD was created in 2011 as a resource to the over 1000 families who have children who are deaf or hard of hearing currently followed at UNC; referrals from outside UNC are now accepted. Under the direction of CIDD psychologist, Dr. Jean Mankowski, the team includes speech-language pathologists Margaret Deramus and Christine Kramer who will serve as clinical mentors for grant trainees. The HDC team also includes occupational therapist, Caroline McCarty, physical therapist, Dana McCarty, and school psychologist/education specialist Casey Okoniewski. According to Dr. Roush, "this is a great example of how programs at UNC work together to combine clinical services with specialized training opportunities for future clinicians."

Special Olympics North Carolina Names Dr. Michael Milano Its First Golisano Health Leadership Award Honoree



Dr. Michael Milano

North Carolina Leadership Education in Neurodevelopmental and Related Disabilities (NC-LEND) Faculty Member, Dr. Michael Milano named as the 2016-17 Golisano Health Leadership Award honoree - North Carolina's top Special Olympics health honor for contributions toward inclusive health.

"Dr. Milano's dedication to the dental health of Special Olympics athletes is second to none. Throughout his 20 years of involvement in two states, he has screened and coordinated follow up care for thousands of athletes as well as bringing new dental professionals into the Special Olympics movement through Special Smiles. Special Olympics athletes in North Carolina are exceptionally lucky to have health professionals like Dr. Milano in the state," explained Special Olympics NC President/CEO Keith L. Fishburne.

Dr. Milano has volunteered with the Special Smiles discipline for two decades in Connecticut, Texas and North Carolina. He became a clinical director in 2001 while working in Texas and has served in that role for North Carolina since 2008, providing free dental screenings, oral hygiene instruction, mouth guards and arranging follow-up care for thousands of Special Olympics athletes. During this time, he has recruited in excess of 1,000 Special Smiles volunteers, the majority of whom have been dental students or pediatric dentistry residents who continue to volunteer their time and expertise with Special Smiles and welcome patients with intellectual disabilities in their dental practices.

As a faculty member at the University of North Carolina School of Dentistry, Dr. Milano has leveraged a partnership with the Dental School to increase access to quality dental care for individuals with intellectual disabilities. His statewide list of over 50 dental providers who welcome patients with intellectual disabilities is made available at every Special Smiles screening so athletes can find appropriate follow-up care.

"I have been scared of the dentist for as long as I can remember, but I knew that my dental health was not where it should be. Dr. Milano has helped me find a dentist who I feel comfortable visiting and is ready to help me improve my dental health," explained Kristine Hughes, a Special Olympics Wake County athlete.

In addition to 20 years' worth of donated time and expertise, Dr. Milano has further contributed to the financial stability of the Special Smiles program by assisting with grant applications. His work to advance the health status of individuals with intellectual disabilities has led him to serve on multiple committees and advisory groups as well as teaching continuing education courses about providing dental care to patients with disabilities. He has also conducted and published research in peer-reviewed journals on such topics as dental students' attitudes regarding treating patients with intellectual disabilities, barriers to dental care for patients with intellectual disabilities and the unmet dental needs of individuals with autism.



Research & Treatment of Mental Illness

Drs. Joseph Piven, Mark Zylka and Jason Stein Awarded Foundation of Hope Research Grant

Early (pre-symptomatic) brain overgrowth has emerged as a primary mechanism underlying the development of later autism in a subset of infants at high familial risk for this disorder. Understanding the genetic basis of brain overgrowth will enable the development of a genetic tool (genetic risk score for brain overgrowth) for identification of infants at increased risk for the overgrowth form of autism in the general population.

The Foundation of Hope has awarded a \$40,000 grant to Joseph Piven, M.D., Mark Zylka, Ph.D. and Jason Stein, Ph.D. to take a first step towards developing this tool (genetic risk score for brain overgrowth) by first identifying genetic variants associated with precursors of brain overgrowth (hyper-proliferation of neural progenitor cells) in a large sample of human neural progenitor cells.

Dr. Peter Duquette, Team Neuropsychologist to the Carolina Hurricanes

CIDD Psychology faculty member, Peter Duquette, serves as the team neuropsychologist to the Carolina Hurricanes of the National Hockey League (NHL). Every pre-season, he conducts brief cognitive evaluations to establish a baseline level of functioning for each Hurricanes player in the event of a concussion during the season. When this occurs, Dr. Duquette provides a more comprehensive assessment of neurocognitive functioning to assist the team physician and athletic trainer on deciding when the player is ready to return to the ice.

This year, several LEND psychology trainees were able to participate in the pre-season baseline testing as part of their training experience. Pictured below left to right from ice level at PNC Arena are Paul DeMello, Whitney Griffin, Maya Mosner, and Dr. Duquette.



Dr. Matthew Judson Publishes in the Journal of Neuroscience



Microcephaly is a hallmark of Angelman syndrome (AS), a debilitating neurodevelopmental disorder that results from loss of function of the HECT domain E3 ubiquitin ligase, UBE3A. However, until recently, the underlying causes of slowed brain growth in individuals with AS had gone unstudied, resulting in significant gaps in understanding of the pathogenesis of the disorder.

A team of scientists led by Ben Philpot at the UNC Neuroscience Center used complementary MRI-DTI, light microscopy, and electron microscopy approaches in AS model mice to show that the growth and integrity of white matter pathways are preferentially affected in the developing brain as a consequence of UBE3A loss. Deficient white matter development thus appears to largely account for the microcephaly phenotype. Philpot and colleagues also found that white matter deficits in AS mice correlate with defects in nerve conduction, which may contribute to motor dysfunction and perhaps other behavioral phenotypes commonly observed in individuals with AS. The study was published on August 2, 2017 in The Journal of Neuroscience.

Matthew Judson, PhD, pictured above, is a Research Associate in the Philpot Lab. To read the full publication, [click here](#).

Variations of a Full Life: A Panel Discussion with Disability Rights Advocates

In September 2017, the CIDD Community Talk Series presented “Variations of a Full Life: A Panel Discussion with Disability Rights Advocates.” Former LEND trainee and current LEND faculty member, McCafferty, Bryan Dooley, D Jones, and Cheryl Powell, advocates in the field of disability rights who happen to have disabilities themselves, shared their individual stories and spoke about the importance of understanding variations of what it means to live a full life as an adult with a disability. They also discussed how the panel’s experiences might support the next generation’s success. Pictured below from left to right is Bryan Dooley, Cheryl Powell, and D Jones.



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