



**Inside the Institute**  
Newsletter for the Carolina Institute for Developmental Disabilities

Issue # 26  
April 2019

**April is National Autism Awareness Month!**



Mark Shen, PhD

**Paper By CIDD Faculty Makes Top 10 List**

The science staff and advisors of Autism Speaks, a leading advocacy group for people with autism spectrum disorder and their families, highlighted the Top 10 studies of 2018 that “most powerfully advanced our understanding, treatment, and support of people on the autism spectrum, selected from over 2,000 peer-reviewed research reports published in scientific journals this year”. On the Top 10 list this year is a paper published in *Lancet Psychiatry* in November by Mark Shen, PhD, assistant professor at the Carolina Institute for Developmental Disabilities and in the Department of Psychiatry.

The study, titled "Extra-axial cerebrospinal fluid in high-risk and normal-risk children with autism aged 2-4 years: a case-control study," enrolled 159 children with autism, ages 2 to 4 years, and found that, as a group, the children with autism had increased cerebrospinal fluid surrounding the brain compared to typically developing children the same age.

It is the third independent study to document this association between autism and increased cerebrospinal fluid around the brain, as seen with magnetic resonance imaging (MRI). The earlier studies studied infants in families already affected by autism. They found that increased fluid was evident by 6 months of age in babies who would later go on to be diagnosed with autism. The earlier studies showed that increased fluid persisted until at least 24 months of age. The new study extends this finding to 4 years of age in children with autism, both with and without a family history of autism.

Taken together, these studies are of great interest because recent research has discovered that cerebrospinal fluid has important functions in brain health: CSF bathes the brain with growth nutrients and helps remove inflammatory cells and other metabolic products that may affect brain development. This is the second year in a row one of Shen's papers made the Autism Speaks Top 10 list. Two other papers of his made the list last year as well. Last year, Dr. Shen earned the Young Investigator of the Year Award for his innovative autism research.

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**Kenneth Kelty Receives CIDD IMPACT AWARD**

Congratulations to Kenneth Kelty, recipient of the Carolina Institute for Developmental Disabilities (CIDD) IMPACT AWARD. The award was established in 2016 to recognize 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. Mr. Kelty completed the University Participant Program at Western Carolina University and was a leadership trainee in the NC Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program in the Self-Advocacy discipline. He continues to be active as a motivational speaker on his experience with autism and full inclusion on a college campus. Pictured left to right: Kenneth Kelty receives the 2018 CIDD IMPACT Award from CIDD Director Joe Piven.



This month marks the third anniversary of UNC's participation in the largest genetic autism research study in the United States. UNC is one of 25 clinical sites to partner with the Simons Foundation Powering Autism Research for Knowledge study. The research initiative is a nationwide effort to gather genetic information from 50,000 participants on the autism spectrum and their biological parents to advance autism research.

Gabriel Dichter, PhD, director of research at the Carolina Institute for Developmental Disabilities, said one of the main goals of the SPARK project is to help determine the genes that cause autism.

"The other goal is, for down the road, to use that genetic information to help us conduct research that evaluates the potential to link individual patients with autism to particular interventions based on their genetic signature, if you will," Dichter said. "Our hope is that this will help guide us down the path of personalized medicine to be able to match patients to treatments based on what we know about their genetics."

UNC's initial involvement in the SPARK project began in early 2016 as one of three pilot sites before the larger national launch in April of the same year. Dichter said UNC has been able to play an integral role in the research study due to an "ongoing relationship" between the Carolina Institute for Developmental Disabilities and nearly 7,000 families who have members with autism.

This community of families, as well as therapy programs and other resources offered by UNC's TEACCH Autism Program, has been instrumental in finding interested individuals to participate in the SPARK study.

Dichter said participants are first directed to an online registration and consent process, where they answer survey questions. Then, they receive a kit in the mail, where the study participant with autism and their family members provide saliva samples. Dichter said the Simons Foundation processes the DNA samples and if they detect a "meaningful" genetic profile, they send the results of their genetic analysis to the family's physician or a genetic counselor to help the family interpret the data.

"Saliva grosses me out and I was able to do it," said SPARK study participant and Durham resident Josephine Arguelles. "And my kids loved it, they thought it was the best day, like my seven-year-old was over there power-spitting into this tube, he thought it was great." Arguelles' older son, Eric, was a part of a TEACCH program to help him with his anxiety, which is how her family originally found out about SPARK. "This is the first place that we lived that we were able to get Eric into programs like this, that had them close by, that had them readily available," Arguelles said. "And we feel a lot of support in the community for children like Eric. This is the first time I've really felt supported as an autism parent."

Arguelles said she found the process to be "really simple" and hopes the study will give her family some answers.

"A lot of parents blame themselves," Arguelles said. "'Was it something we did? Was it something we didn't do?' And so I think [the research] would bring at least some comfort to families, at least we would know the when, the how, and the why."

UNC SPARK Study Coordinator Corrie Walston said more than 1,800 people with autism and their family members have enrolled in the study through UNC. There are no limitations to participants with regard to age or diagnoses, Walston said. "The autism spectrum is huge and they want as many people to participate as possible because autism is so heterogeneous," Walston said. "No two people with autism look alike."

There are currently 16,712 families enrolled in the research study. April 2nd marked the 12th World Autism Awareness Day, which was established by the United Nations General Assembly in 2008. "Really, World Autism Awareness Day for us is about thanking the families that we've worked with in research for their dedication, because without them, research would not be possible and without the research, a better outcome could not be possible for their children," Dichter said.

Arguelles said she hopes the SPARK project will provide her family with guidance to help Eric as he gets older. "He's really opened our eyes and we see the world differently because of him. But he does struggle and that's hard to watch," Arguelles said. "... I hope that whatever they find that we can benefit from it, that we can use it. We really want Eric to be successful."

## Art Meets Science in “The Beautiful Brain”

On February 8, 2019, the Ackland Art Museum at the University of North Carolina at Chapel Hill hosted a gallery talk led by neuroscientists from the UNC Neuroscience Center and CIDD, Intellectual and Developmental Disabilities Research Center (IDDR) Investigators, who spoke about their images featured in “The Beautiful Brain: The Drawings of Santiago Ramón y Cajal.” Jessica Girault, a postdoctoral research fellow at the CIDD, presented her artwork which was selected from a pool of modern art submissions made by UNC neuroscientists. The artwork depicted white matter fiber pathways in the infant brain generated using MRI. This image was created as part of her dissertation work studying the associations between structural brain maturation and cognitive development in the first two years of life under the direction of Dr. John Gilmore in the Department of Psychiatry.



Jessica Girault is pictured above presenting her image featured in the Ackland Art Museum's exhibition, “The Beautiful Brain.”

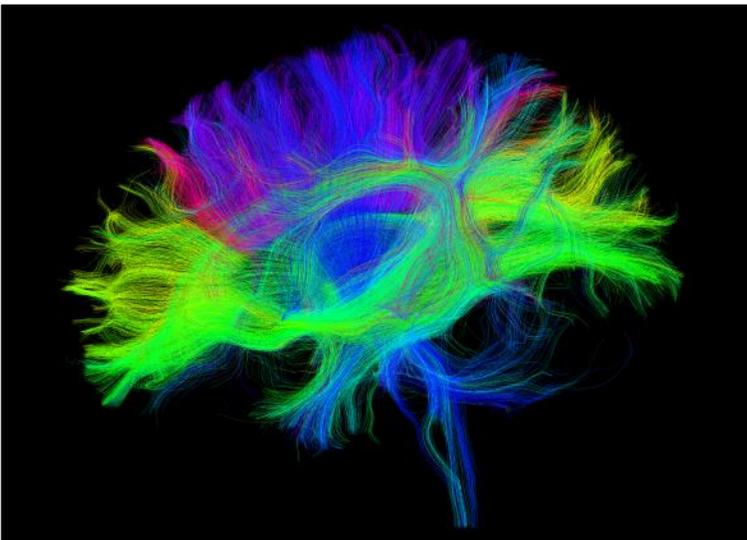


Image Description: White matter fiber bundles in the human brain are organized during gestation and mature rapidly following birth. Magnetic resonance imaging, or MRI, is the primary method used for studying the developing human brain *in-vivo*. We can use a special type of MRI, called diffusion tensor MRI, which captures diffusion patterns of water molecules in brain tissue, to trace bundles of axons connecting different regions in the brain. Using this method, we can reconstruct major fiber pathways, which can be thought of as information highways, in the brain. This image shows the major fiber pathways reconstructed from an MRI of a 1-year-old infant.

## Dr. Michelle Itano Earns CZI Grant to Support Imaging Scientists



*Michelle Itano, PhD*

The Chan Zuckerberg Initiative (CZI) announced \$17 million in funding of 17 CZI Imaging Scientists, including Michelle S. Itano, PhD, director of the CIDD-IDDRC Microscopy Core, who will receive approximately \$780,000 to work with UNC-Chapel Hill scientists.

The Microscopy Core, which is funded by the UNC Neuroscience Center and the UNC Intellectual and Developmental Disabilities Research Center, is now housed in the newly reconstructed state-of-the-art Mary Ellen Jones Building. The grant will support Itano's work in full over the next five years to help increase the interactions between biologists and technology experts and to improve imaging tools for the scientific community at UNC-Chapel Hill.

Itano received her doctorate degree from the UNC School of Medicine, did her postdoctoral work at The Rockefeller University, and is now an assistant professor in the Department of Cell Biology and Physiology at UNC-Chapel Hill. She uses an interdisciplinary approach to develop and apply new and innovative fluorescence microscopy imaging techniques to answer critical and previously intractable questions in cell and neurobiology.

She has developed and applied advanced microscopy techniques, cell biological applications, and quantitative image analysis to uncover important relationships between proteins, non-coding RNAs, viral RNA genomes, and other building blocks of

basic biology. Through her expertise, she helps scientists at UNC-Chapel Hill and the surrounding area make crucial discoveries about human health and disease.

As director of the CIDD-IDDRC Microscopy Core at the UNC Neuroscience Center, she provides and customizes state-of-the-art optical imaging and analysis applications to support a wide range of scientific investigations. She trains scientists at UNC-Chapel Hill and consults with them to fully address their imaging needs through her expertise.

Itano is the first UNC-Chapel Hill researcher to receive a CZI grant. Read more about [these awards at CZI](#) and [Medium](#).

## Best Buddies Brews (B3) Creates Opportunities for Inclusion

Started by UNC senior Jacklyn Googins, Best Buddies Brews (B3) is a pop-up coffee stand that promotes inclusion through gainful volunteer opportunities, friendship, and coffee. The stand is run by adults with intellectual and developmental disabilities (I/DD), and it serves as a platform for volunteers to showcase and develop marketable skills and engage with the community. Jacklyn is a UCEDD Intern from the Human Development and Family Studies program at the UNC School of Education. The B3 crew includes Anna Coleman, LEND trainee in Self-Advocacy.

B3 pops-up at various community and on-campus venues 2-3x per month. Best Buddies Brews offers high quality, specialty coffee and 3 different brewing methods: french press, pour over, and drip coffee.

To learn more visit:

<https://bestbuddiesbrews.com>





## NC-LEND Trainee Symposium 2019

As the 2018-19 academic year comes to a close, our exceptional cohort of **North Carolina Leadership Education in Neurodevelopmental and Related Disabilities (LEND)** trainees will present their LEND projects on April 17 and 24, 2019. The cohort represents a combination of interdisciplinary graduate students, self-advocates and family members who have put in a minimum of 300 hours focused on IDD-related learning, community-based, clinical and/or research activities. The annual Trainee Symposium is held each spring and allows an opportunity for each trainee to highlight an area of interest and focused work. Trainees and their presentation titles are listed below:

### APRIL 17

TRAINEE	PROJECT	DISCIPLINE
Sarah Furlong	Resting EEG Connectivity Markers of ADHD in Early Childhood: An Approach With Potential Utility for Neurodevelopmental Disorders	Psychology
Alex Alvarez Rivas	Outcome Evaluation of a Sexuality and Relationship Education Group for Adolescents with Developmental Disabilities and their Parents	Social Work
Chelsea Lasky	Adaptive Equipment for Children with Intellectual and Developmental Disabilities	Physical Therapy
Paige Landau	Testing Accommodations for Individuals with I/DD	Psychology
Tina Braimah	Contraceptive Choices for Women with Intellectual Disabilities	Family
Cheryl Walfall-Flagg	ABLE Accounts: What is an ABLE Account? A Parent Perspective	Family
Rahma Hida	An Information Flyer about ASD for Arabic-Speaking Families	Education
Rachel Greene	Using Eye Tracking to Predict Social Skills Treatment Outcomes in ASD	Psychology
Aimee Durrett	Family Resource Binder for Newly Diagnosed Cases of Angelman Syndrome	Genetic Counseling
Arielle Abrams	A Single Case Study of Bimodal Listening	Audiology
Danielle Hamlin	Outcomes Following Special Olympics Healthy Hearing Screenings	Audiology
Liz Jaramillo	Where is Bear? A Terrific Tale for 2-Year-Olds/ ¿Dónde está Osito? Un fantástico cuento para niños de 2 años	Speech Language Pathology

### APRIL 24

Kelly Caravella	Longitudinal Social Communication Comparisons in Preschool Age Children with Down Syndrome and Fragile X Syndrome	Psychology
Demi Eckhoff	Locked-In: A Review of Current Legislation Addressing Portability of Medicaid and Its Long-Term Services and Supports	Nutrition
Anna Coleman	Teaching High School Students about Participating in Their IEP Meeting	Self-Advocacy
Kendyl Cole	Community Formation Through A Dinner Club for Adults with ASD	Occupational Therapy
Chelsea Snell DeAngelis	A Proposal for a Digital Based & Family Centered Parent-Implemented Intervention for Addressing Feeding Problems in Children with ASD	Nutrition
Jill Sirko	An Information Packet for Parents of Children with Significant Disabilities and Complex Communication Needs	Family
Salma Baig	Project Believe- Braking Barriers to Mental Health Treatment in the Muslim Population	Psychology
Maggie Holland	Importance of Early Mobility for Children with Disabilities	Physical Therapy
Emily Holding	Using Technology to Support Parent Behavior Management Training	Psychology
Christine South	Increasing Positive Predictive Value for Likelihood of Autism in Infants using a Dynamic Systems Approach	Speech Language Pathology
Jenna Sawafta	Hearing Aid Education Videos for the Middle Eastern Refugee Population	Audiology
Senyene Eyo Hunter	Anesthetic Drugs and Neurodevelopmental Outcomes in Premature Infants	Neurology

## Djenne Morris, NC-LEND Multicultural Specialist, Winner of National Leadership Award

Ms. Djenne Morris, who serves NC-LEND as a multicultural specialist and advocate for parent-professional collaboration, is a 2019 recipient of the EHDl Family Leadership Award, presented at the national EHDl meeting in Chicago on March 8th. EHDl, an acronym for "Early Hearing Detection and Intervention," refers to the nationwide effort to screen all newborn infants for hearing loss and provide early diagnosis and intervention for those with congenital hearing loss. LEND director Dr. Jack Roush notes: "Family members are key stakeholders in the EHDl process and nominations for the Family Leadership Award are submitted from across the U.S. Djenne's leadership and advocacy have had a major impact in North Carolina as well as nationally and internationally. It's hard to imagine a person more richly deserving of this prestigious award."

In addition to her work with NC-LEND, Ms. Morris is employed by 'Beginnings', a program that provides support to families with children who are deaf or hard of hearing. She also serves as president of the board for the national Hands and Voices organization. Djenne and her husband, Michael, have two daughters, Imani and Zakiya, and a son, Malik, who was born with deafness and multiple disabilities.



*Djenne Morris and her son, Malik.*



NC-LEND trainees (L-R) Madeline Barclay, Arielle Abrams, Djenne Morris, Jack Roush (LEND Director), Ashley McMillen, Megan Bartoshuk, and Christine South.

## The North Carolina Intellectual Developmental Disabilities Medical Health Home Initiative and Related Efforts



*Dr. Robert Christian*

In 2013, the North Carolina Council on Developmental Disabilities, a “sister” organization to CIDD through the DD Network, began to sponsor an effort called the Intellectual Developmental Disabilities (I/DD) Medical Health Home Initiative ([www.iddmedicalhealthhomencinitiative.com](http://www.iddmedicalhealthhomencinitiative.com)). This effort brought together an array of stakeholders to develop recommendations regarding the need for improvements in the health care system for individuals with I/DD.

Dr. Robert Christian, MD, a CIDD pediatrician and psychiatrist, has been involved with the effort as a stakeholder and consultant since the initiative’s inception. The original I/DD Health Home Initiative brought a new level of attention to many needs in this realm including: the need for enhanced coordination between the state funded I/DD system (currently managed via contracts with managed care organizations - MCOs, and the physical health, improved family support and I/DD system navigation, and enhanced education regarding I/DD health issues in primary care.

The I/DD Health Home Initiative has since spun off several efforts through different funding sources in an attempt to more directly address these gaps. Two such related spin off projects include The North Carolina Pediatric Access Line for Intellectual and Developmental Disabilities (NC-PAL I/DD) and UNC’s Project ECHO Autism. Dr. Christian and CIDD is a key partner in both efforts. Leaders of the efforts include Karen Luken with Easter Seals NC for the I/DD Health Home Initiative; Dr. Gary Maslow, MD pediatrician and psychiatrist at Duke for NC-PAL I/DD; and Drs. Laura Klinger and Nicole Ginn Dreiling with UNC TEACCH.

The NC-PAL I/DD project is a partnership between Duke University Integrated Pediatric Mental Health, UNC General Pediatrics, CIDD and NC START Central team, that aims to improve the care of children, adolescents, and young adults with intellectual/developmental disabilities (I/DD) by providing a reactive telephone consultation phone line and engaging in proactive strategies for case finding and care management in two pilot primary care sites.

NC-PAL I/DD offers telephone consultation providing information to parents and providers in real time and a Family Partner (parent-to-parent peer support provider) is available to meet with families during clinic visits to provide resource identification, emotional support and systems navigation support. Major accomplishments of the program to date include completion of a comprehensive case identification process and chart review of 500 primary care patients, development of a resource packet offering an overview of the I/DD system, and individual telephone outreach to families.

Through additional funding, there has also been an examination of data from the North Carolina Educational Data Research Center with a focus on better understanding the prevalence of I/DD in North Carolina and the intersection of race, ethnicity, and economic status on identification, classification and access to resources.

UNC’s Project ECHO Autism is based out of UNC TEACCH and has adapted and piloted a notably different web-based teleconsultation model (Project ECHO) to support both medical and mental health providers in integrated primary care practices in rural eastern North Carolina. Project ECHO is an online learning and guided practice model that links professionals in local communities (“spokes”) with specialist care teams (“hubs”) that includes a psychiatrist, psychologist, parent liaison, and autism specialist from TEACCH, CIDD, and the Autism Society of NC. It is hosted in a teleconsultation format involving a mix of didactic presentations and in-depth case consultations.

To date, UNC’s Project ECHO Autism has been offered to a total of 5 cohorts across eastern NC including 39 mental health providers and 49 primary care physicians both in rural practices and on base serving military families. Initial results have shown high levels of satisfaction with the model as well as significant changes in providers’ autism knowledge and self-efficacy for providing treatment and resources to families.

Dr. Christian serves as a clinical consultant with both projects and a didactic instructor with the UNC Project ECHO Autism. These two models are currently being evaluated for their effectiveness. A longer term goal includes a movement towards more synergy between the two efforts and further expansion of the effort(s) in North Carolina.

## Faculty Spotlight: Dr. Diana Cejas



*Dr. Diana Cejas*

Diana Cejas, MD, MPH, is a pediatric neurologist who joined CIDD faculty in July 2017. She received her MD at Howard University and a Masters of Public Health in Maternal and Child Health at the George Washington University. She trained in general pediatrics in the Tulane University – Oschner Health System Pediatric Residency Program before moving on to child neurology at the University of Chicago.

Dr. Cejas' research interests center upon the transition from pediatric to adult healthcare systems for youth with neurodevelopmental disabilities. Since coming to UNC, she has joined the STARx Transition Research Team and has served as co-investigator for studies that examine transition readiness and the psychosocial effects of transition. Her other projects include a quality improvement initiative that aims to increase the percentage of patients who receive healthcare transition services at CIDD. Her ultimate goal is to develop novel interventions aimed at improving communication between patients, families, and healthcare providers and improving care delivery as it relates to healthcare transition.

In the neurodevelopmental medicine clinic, Dr. Cejas provides neurological evaluation and treatment for children, adolescents, and young adults with developmental disabilities and co-occurring neurological conditions including epilepsy, headache disorders, sleep disorders, and more. Additional services she provides include healthcare transition counseling and planning. She is also a member of the neurogenetics clinical team and provides neurological consultation services to other CIDD multidisciplinary teams.

In addition to her clinical work and research, Dr. Cejas has authored a growing number of essays, opinion pieces, and other works of narrative medicine. These pieces have appeared in health-centered websites and blogs including Op-Med: Voices from the Doximity Network and KevinMD.com, medical journals including The Journal of the American Medical Association and Neurology, literary magazines including Catapult, Passages North, the Intima, and others.

## Andrea Baldelli Joins T32 Post-Doctoral Research Training Program



Andrea Baldelli, PhD, received her doctorate in Clinical Psychology and Neuroscience from the University of Colorado Boulder under the mentorship of Dr. Vijay Mittal. Dr. Baldelli's dissertation examined social reward processing in adolescents at risk for psychotic disorders such as schizophrenia using functional magnetic resonance imaging. Her earlier graduate school work was similarly focused on the neural basis of social behavior, social communication, and psychotic related symptomatology. Dr. Baldelli joined the CIDD T32 program to continue this line of work under the guidance of Dr. Aysenil Belger. She has joined an ongoing project that studies stress, working memory, and cognitive disorganization in children and adolescents in order to further our understanding of psychosis risk and the interaction between stress and neurodevelopment. Dr. Baldelli's work will use this data to examine structural and functional connectivity within the brain, social behavior, reward, and cognitive functioning with the overarching goal of understanding the neurodevelopment trajectory of severe mental illness.

## NC-LEND Trainee Travel Award



Clinical psychology doctoral student, Rachel Greene, MA, has been awarded the NC-LEND Trainee Travel Award, which will provide funds for her to attend the International Society for Autism Research (INSAR) 2019 Annual Conference in Montreal, Canada. At the conference, Ms. Greene will be presenting findings regarding neural similarities and distinctions of individuals with autism spectrum disorder (ASD), ADHD, and co-occurring ASD and ADHD. Her conference presentation used data from the publicly available ABIDE and ADHD-2000 datasets to better understand functional connectivity patterns in these overlapping disorders. It is the hope that by better understanding the brain patterns of individuals with ASD and co-occurring ADHD, we may better inform interventions for individuals with both conditions. These analyses were conducted at CIDD in collaboration with Dr. Gabriel Dichter.

## Scientists Create Genomic Resource to Explore the Biological Underpinnings of Brain Disorders



Hyejung Won, PhD

A team of researchers, including scientists from UNC School of Medicine, has developed a model of unprecedented sophistication that relates variations in DNA and gene activity to the risk of brain disorders.

The model, described in a [paper published in \*Science\*](#), draws from prior studies of thousands of healthy people and people with brain disorders. Scientists can now use it as a tool to explore the biological mechanisms of disorders such as schizophrenia and autism, which have largely eluded a deep understanding and have no cure.

“It’s the most comprehensive functional genomic resource ever developed for understanding the brain, and it establishes a framework for integrating different kinds of genomics data to get deep insights into the biology of brain disorders,” said co-first author Hyejung Won, PhD, assistant professor genetics at the UNC School of Medicine and member of the UNC Neuroscience Center and Carolina Institute for Developmental Disabilities.

Scientists in the last few decades have performed hundreds of studies that gather DNA-sequence and related data on large groups of people to identify DNA variations and other genome-related factors associated with diseases. These genomics studies have generated important clues to the biological causes of many illnesses. But for psychiatric disorders and many other common brain disorders, traditional genomics studies have been less useful. Schizophrenia, for example, has

been linked to specific variations at more than 100 locations on the genome – called “risk loci” – but most of these loci do not contain genes, so it is unclear how they relate to the disease. Moreover, the many gene variants that have been linked to schizophrenia typically have only weak impacts on schizophrenia risk. This has suggested to scientists that schizophrenia, and probably many other brain disorders, are too complex to understand with traditional, one-dimensional genomics approaches.

In pursuit of a more sophisticated approach, a group of genomics researchers several years ago formed the PsychENCODE consortium. They began to pool data from their genomics studies and other publicly available studies to develop tools to find relationships between different kinds of data. The new resource includes different kinds of genomics data on individuals who had schizophrenia, bipolar disorder, and autism spectrum disorder. The types of genomics data include DNA-sequences, data on gene expression from specific kinds of brain cells, maps of DNA regions called “enhancers” that promote gene expression, and other features of the genome known to affect gene activity.

Won contributed data from her own studies on “chromosome conformation.” This refers to the three-dimensional organization of looped DNA in the nuclei of cells, and in particular the points where different loops come close enough to influence each other’s gene expression. Won also developed a complex model of how gene expression in brain cells is regulated by chromosome conformation and other genomic factors.

The team used the gene regulation network model to evaluate 142 schizophrenia risk loci uncovered by prior genomics studies. These risk loci do not contain genes, but are suspected of contributing to schizophrenia risk by somehow influencing the expression of other genes. The model identified 321 genes, including some that are known schizophrenia risk genes, as the likely regulatory targets of these risk loci. Won and colleagues showed that these genes affect the functions of synapses, acetylcholine receptors, ion channels, and other pathways implicated in prior schizophrenia studies. The scientists also determined that schizophrenia is primarily a disorder of neurons, not of other brain cells.

The resource developed for the study includes an AI-powered “deep-learning” model that estimates the risk of psychiatric symptoms based on gene variant and gene expression data. The scientists compared the new model to a standard, much simpler model that predicts psychiatric illness based on an individual’s genome. “The deep-learning model was much more accurate, and we think it will have a big impact in terms of risk assessment and diagnosis for patients,” Won said.

She and her PsychENCODE colleagues now are continuing to develop their model by integrating more types of genomics data and extending their analyses beyond schizophrenia to other brain disorders.

*The senior authors of the study were Daniel Geschwind, MD, PhD, of UCLA’s Geffen School of Medicine, James Knowles, MD, PhD, of SUNY Downstate Medical Center College of Medicine, and Mark Gerstein, PhD, of Yale. The National Institute of Mental Health funded this work.*

## LEND Programs Share Experiences with Assessment of Children Who Are Deaf or Hard of Hearing with Co-Occurring Developmental Disabilities



In 2011, NC-LEND established a clinical program dedicated to the interdisciplinary assessment of children who are deaf or hard of hearing with known or possible neurodevelopmental disabilities. At the annual AUCD conference in Washington DC in November, 2018, representatives from NC-LEND were joined by LEND colleagues from Colorado, Massachusetts, and Ohio for a panel presentation on the benefits and challenges associated with interdisciplinary assessment of children with hearing loss and developmental disabilities. LEND post-doctoral psychology fellow, Dr. Stephanie Fox (right) is joined by Dr. Jean Mankowski, UNC (center), and Dr. Amy Szarkowski (left), Boston Children's Hospital. Other participants included Dr. Debra Mood, Colorado Children's Hospital, Dr. Susan Wiley, Cincinnati Children's Hospital, and Dr. Jackson Roush, UNC.

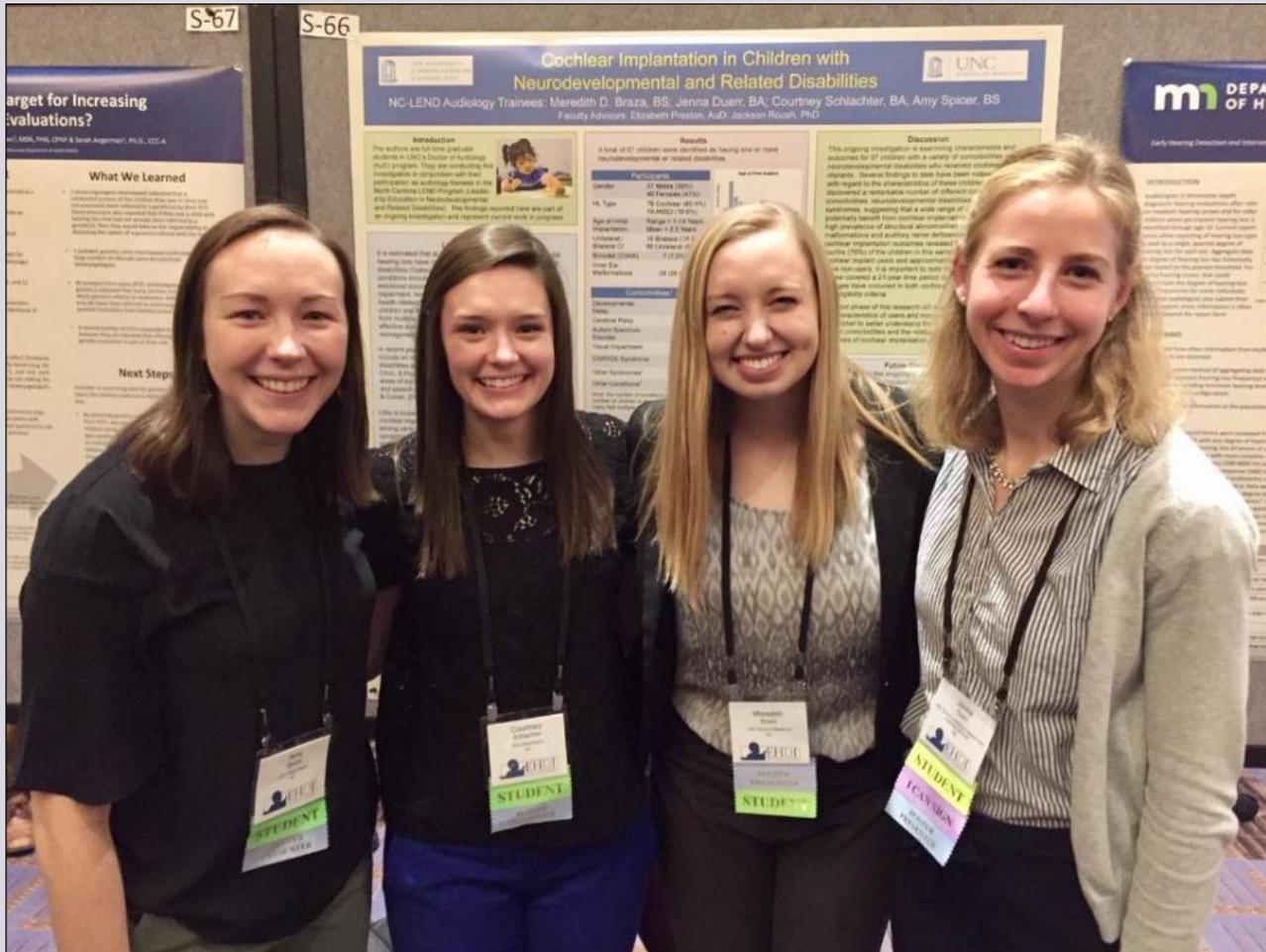


## Anna Coleman Presents Workshop at East Chapel Hill High School

Anna Coleman, LEND trainee in self-advocacy, created and presented a workshop to encourage high school students to attend their annual IEP (Individualized Education Program) meeting. Special Education Teacher Kathleen Laufer welcomed Ms. Coleman to her East Chapel Hill High School classroom and Deb Zuver, Ms. Coleman's LEND mentor, was on hand to support the presentation. Pictured from left to right: Anna Coleman, Kathleen Laufer, and Deb Zuver.

## Audiology Trainees Present LEND Project at National Conference

In 2016, NC-LEND competed successfully for a supplemental grant from HRSA/MCHB to expand the educational preparation of pediatric audiologists who will serve children with autism and other developmental disabilities in addition to deafness. In March, four first year graduate students in UNC's Doctor of Audiology (AuD) program, presented their group LEND project at the national Early Hearing Detection and Intervention (EHDI) meeting in Chicago. The project poster, entitled "Cochlear Implantation in Children with Neurodevelopmental Disabilities" reported preliminary findings for 97 children who received cochlear implants at UNC over a 20 year period. Faculty mentors, Dr. Elizabeth Preston and Dr. Jack Roush, praised the students for their exemplary commitment and teamwork. The project will continue through June, 2019; findings will also be shared at the ACIA 16th Symposium on Cochlear Implants in Children, Hollywood, FL, in July, 2019.



NC-LEND Audiology Trainees (L-R) Amy Spicer, Courtney Schlachter, Meredith Braza, and Jenna Duerr.



Join the UNC/CIDD team participating in the 2019 Angelman Syndrome Foundation (ASF) Walk on Saturday, May 18, 2019 at Southern Community Park—1000 Sumac Road in Chapel Hill, NC. Registration begins at 9 AM. Walk begins at 10 AM. The goal of the ASF Walk is to find treatments and a CURE for Angelman syndrome while lending a hand to families who need it. Learn more: [www.angelman.org/walk](http://www.angelman.org/walk)



CIDD Together with UNCTEACCH Autism Program  
“Light It Up Blue”  
for  
2019 World Autism Awareness Day



### Your Support

The programs of the Carolina Institute for Developmental Disabilities provide innovative, high-quality clinical, research, and training activities supporting individuals with developmental disabilities. Now, more than ever, we need well-trained practitioners, teachers, and researchers. State funds pay only part of the costs to recruit and retain the best faculty and support the unique training and programs that are the hallmarks of the Carolina Institute for Developmental Disabilities experience. It is private funds that sustain and enhance these extraordinary opportunities for students, patients, families, and faculty. We can't do it without you!

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