



UNC

CAROLINA INSTITUTE FOR DEVELOPMENTAL DISABILITIES

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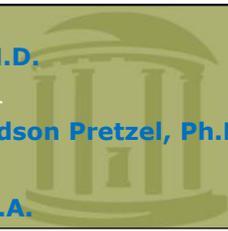
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Inside the Institute

Newsletter for the Carolina Institute for Developmental Disabilities

Issue # 24
April 2018

April is National Autism Awareness Month!

Three UNC Autism Research Studies Earn End-of-Year Honors



Autism Speaks, Spectrum, and the National Institutes of Health singled out innovative work from the Carolina Institute for Developmental Disabilities (CIDD) research teams as top studies advancing the field of autism research in 2017.

The first study, published in *Nature* last February, used MRIs to show that the babies who developed autism experienced a hyper-expansion of brain surface area from six to 12 months. Increased growth rate of surface area in the first year of life was linked to increased growth rate of overall brain volume in the second year of life. Brain overgrowth was tied to the emergence of autistic social

deficits in the second year. The second study, published in *March*, used MRIs to show the differences in cerebral spinal fluid between babies who would develop autism at age 2 and babies who would not develop the condition. The third study, published in *June*, delineated the differences in brain connections using MRIs and computer algorithms.

Autism speaks listed all three studies in the organization's [Top 10 Autism Studies of 2017](#), as judged by the leading advocacy group's science staff and advisors. The selected studies were the ones "that most powerfully advanced understanding, treatment and support for people on the autism spectrum." *Spectrum*, a leading source of news and expert opinion on autism research and formerly part of the Simons Foundation Autism Research Initiative, listed two of the studies in its list of ten "[Notable Papers in Autism Research in 2017](#)." The Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) selected a few examples of the [best innovations made possible through NICHD support](#), including one of UNC's autism studies. Last year, the NIH awarded nine research grants totaling more than \$100 million for the Autism Centers of Excellence, including the center at UNC.

Piven, the Thomas E. Castelloe Distinguished Professor of Psychiatry in the UNC School of Medicine and director of the Carolina Institute for Developmental Disabilities, is on the executive committee of the UNC Autism Research Center. The goal of the new center is to accelerate the creation of more effective, personalized treatments and interventions for the millions of people with autism spectrum disorder across the lifespan.



Dr. Mark Zylka Honored for Advances in Autism

CIDD investigator, Mark J. Zylka, Ph.D., has been named a fellow by the American Association of the Advancement of Science (AAAS), the world's largest general scientific society. Dr. Zylka was one of three professors from UNC-Chapel Hill, and among 396 new fellows in total, who were recognized by their peers for meritorious efforts to advance science and its applications. As part of the Section on Biological Sciences, Zylka was elected an AAAS Fellow for his distinguished contributions to the field of neuroscience, particularly for the study of autism-related genes and risk factors using high-throughput approaches. Zylka is the W.R. Kenan Jr. Distinguished Professor of cell biology and physiology and director of the UNC Neuroscience Center. He won a Hettelman Prize for his work in autism and chronic pain and has also received a five-year, \$3.8M Pioneer Award from the National Institutes of Health to study the [role that genetic and environmental factors play in autism](#).

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A University Center for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD) with core funding from the Administration on Developmental Disabilities (AIDD)

An Intellectual and Developmental Disabilities Research Center (IDDRC) with core funding from the National Institute of Child Health and Human Development (NICHD)

A Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Program with core funding from the Maternal and Child Health Bureau (MCHB)

UNC and Easterseals Form Partnership to Conduct a Nationwide Neuroimaging Study of School-Age Children with Autism

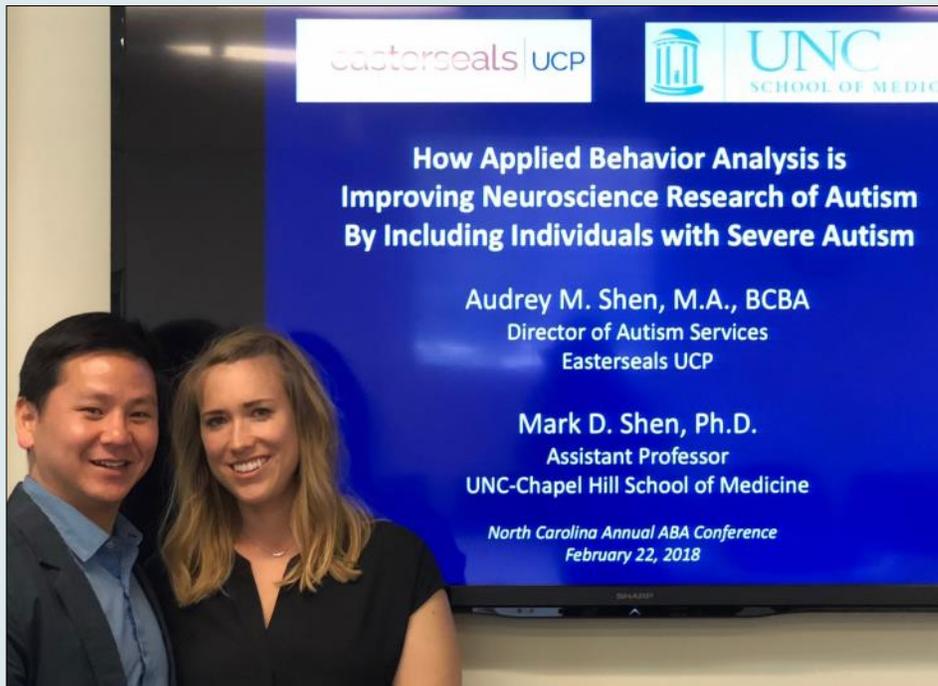
UNC investigators at the CIDD have formed a collaboration with community partner Easterseals to conduct the first longitudinal MRI study of children with autism from infancy to school-age.

A team of CIDD investigators led by Joe Piven was recently funded by NIH to continue the Infant Brain Imaging Study (IBIS; www.ibis-network.org). In the earlier phase of IBIS, children at high- and low-risk for autism were studied with MRI scans throughout infancy to track their early brain development and identify early markers for autism. In the new phase of the study, these children will return for an MRI scan at 7-10 years of age during school-age, a time when many children with autism experience educational and behavioral challenges – and when comorbidities may arise such as ADHD, anxiety, and intellectual disability. Historically, severely affected children with autism were often excluded from neuroimaging studies due to challenges of lying still in the MRI scanner. This limited the understanding of brain development in ASD, since many studies only included “high functioning” children.

The new UNC-Easterseals partnership aims to address this gap by collaborating with Audrey Shen, Director of Autism Services for Easterseals UCP, based in Raleigh. Easterseals is a national non-profit organization that provides community-based treatment and services for individuals with developmental disabilities.

Ms. Shen is a board-certified behavior analyst (BCBA), and she previously published a methods paper in which she developed behavioral methods to teach children with autism to successfully lie still in the MRI scanner while detailed scans of their brain were acquired. In the new partnership, she will now train IBIS teams at 4 universities across the U.S. to implement these methods to acquire successful MRIs of children across the autism spectrum, regardless of their ability.

Joe Piven, Director of CIDD and PI of the IBIS Network said: “We were extremely fortunate to have Audrey Shen help us with this study. Her skills in teaching children with autism, and particularly in training children with autism to lie still in the scanner, are critical to our study’s success. Her recent paper with husband Mark Shen has set the standard for the field and has allowed children with autism to be included in such studies, which previously excluded those children with co-occurring intellectual disability.”



The UNC-Easterseals partnership was kicked off in February when Audrey and Mark Shen (pictured left) co-presented a research talk at the annual Applied Behavior Analysis (ABA) conference entitled: “*How ABA is Improving Neuroscience Research of Autism by Including Individuals with Severe Autism*”. Based on the response following the talk, the President of the conference invited them to return next year as the featured keynote speakers of the conference.

In addition to Dr. Piven, the UNC IBIS team includes: Mark Shen, Chad Chappell, Martin Styner, Heidi McNeilly, Rachel Smith, Leigh Anne Weisenfeld, Meghan Swanson, Mike Graves, Sun Hyung Kim, and Heather Hazlett (UNC site PI).

Chad Chappell, study coordinator of the IBIS Network said: “It’s very exciting that subjects of varying abilities will be able to participate in our study because we are making an MRI scan a fun and successful experience. Not only will the resulting data be invaluable to the autism field, but we also think the kids in our study will find this experience to be very rewarding and enjoyable.”

Audrey Shen added: “Through this partnership, UNC and Easterseals are working to ensure that children with autism at all levels are represented in autism research. I am very proud to work together with UNC to lead this important effort.”

Congratulations to CIDD Investigator, Dr. Spencer Smith Recipient of the 2017 Hettleman Prize

HETTLEMAN LECTURES

Presentations by two of UNC's most distinguished young scholars—
winners of the 2017 Phillip and Ruth Hettleman Prizes for Artistic and Scholarly Achievement



Wednesday, April 25th 2018
1:00 PM—3:30 PM
G100, Bondurant Hall
UNC-Chapel Hill Campus

Spencer Smith, PhD,
Associate Professor of Cell Biology and Physiology
Presenting at 1:00 PM
It's Full of Stars: Telescope-like Optics for Panoramic
Views of Neurons in Action in the Living Brain



James Cahoon, PhD
Associate Professor of Chemistry
Presenting at 2:00 PM
Architectural Nanomaterials: Designing
Semiconductors So Form Follows Function

Announcing the UNC School of Social Work's First Course on Autism Spectrum Disorder



First Summer Session
Fridays, May 18 - June 15, 2018 – 9 AM – 12:00 Noon

SOWO 709 - Autism Spectrum Disorder: Social Cognitive Interventions – 1.5 credits
Instructor: CIDD LEND Faculty, Sherry C. Mergner, MSW, LCSW

This course provides an overview of the core social cognitive challenges faced by individuals with autism spectrum disorder (ASD). Selected evidence-based interventions will be reviewed with ASD across populations and contexts. This graduate course is open to social work, education, speech and language, occupational therapy and psychology students as well as anyone interested in working with this population.

CIDD Community Talk Series Presents

“Residential Options for Adults with Autism”

The CIDD hosts a series of talks to share information about recent advances in developmental disabilities. These sessions are a great opportunity for parents, teachers, professionals, and others to learn more about specific developmental disabilities topics. All talks are free, and everyone is welcome. Our March talk, “Residential Options for Adults with Autism,” provided a starting point for parents to begin planning for the adult phase of parenting a child on the autism spectrum. Factual information was presented on current residential options ranging from independent living to a group setting. Information related to possible funding streams were also discussed. Speakers were Kerri Erb, Autism Society of North Carolina (ASNC) Chief Program Officer, Kim Tizzard, ASNC Director of Family Support, and Maureen Morrell, parent of a child with ASD.

Navigating the world of services for your loved one with autism can be complicated and confusing at times. ASNC's online resources can help:

[Accessing Services](#)
[ASNC Toolkits](#)



Mark Shen Awarded the 2018 Young Investigator of the Year Award from the International Society for Autism Research



Mark Shen, Assistant Professor at the CIDD, has been awarded the 2018 Young Investigator of the Year Award from the *International Society for Autism Research (INSAR)*, the largest international scientific organization of autism researchers. This award is given once a year to the early-career investigator (i.e., earned their doctoral degree within the past 7 years), who published the best empirical research paper of the year.

Dr. Shen and several colleagues at the CIDD—Heather Hazlett, Martin Styner, Meghan Swanson, and Joe Piven—reported that infants who later developed autism had increased levels of extra-axial cerebrospinal fluid in the brain at 6 months of age, which preceded the onset of autism symptoms, and predicted their later autism diagnosis and severity of symptoms at two years of age (*Shen et al., 2017; Biological Psychiatry*). This was the first replication of an infant brain anomaly in autism. This research was also recognized by *Autism Speaks* as one of the “Top 10 Papers of Year” and was nominated by the *NIH Interagency Autism Coordinating Committee (NIH IACC)* as a finalist for their annual list of “the most significant advances in autism research”. Dr. Shen will receive the award during the awards ceremony at the annual INSAR Conference—the international conference for autism research—held this May in the Netherlands.

NC-LEND Sponsors Statewide Conference on Diagnosis of Autism in Children With Hearing Loss

Over 160 people including students, faculty, parents and practitioners from multiple disciplines across the state attended a full day conference on screening and diagnosis of autism in children who are deaf or hard of hearing. The meeting was offered in cooperation with the North Carolina Early Hearing Detection and Intervention (EHDI) program within the NC Division of Public Health and featured two nationally recognized authorities. Robert Nutt, MD, a developmental-behavioral pediatrician and former LEND fellow recently moved from Rochester NY to the Charlotte area where he is now practicing with Atrium Health. Dr. Nutt, who was born with severe hearing loss and is fluent in both spoken English and American Sign Language, defined “Deaf Plus” which includes conditions that can co-occur in this population, emphasizing the importance of facilitating communication development in the optimal modality for each child. Christine Yoshinaga-Itano, PhD, from the University of Colorado – Boulder, Institute of Cognitive Science, whose research was instrumental in paving the way for universal newborn hearing screening in the US, reviewed screening and diagnosis in this population with emphasis on characteristics that differentiate children, with and without autism, who are deaf or hard of hearing. NC-LEND director, Dr. Jack Roush, noted: “We were very pleased with the interest in this topic; in fact the response exceeded our expectations. Even after moving to a larger venue we still had a waiting list.” NC-LEND will continue to provide educational programs and technical assistance in this area along with clinical services at CIDD through the Hearing and Development Clinic.



(First picture-left to right: Dr. Nutt and Dr. Yoshinaga-Itano. Second picture: Becky Pretzel, CIDD Associate Director; Dr. Yoshinaga-Itano; Jean Mankowski, Director of Training NC-LEND; Dr. Nutt; Jack Roush, Director of NC-LEND and the Division of Speech and Hearing Sciences)



Graham Diering Selected as Finalist for Eppendorf & Science Prize for Neurobiology

Graham Diering, PhD, assistant professor of cell biology and physiology at the UNC School of Medicine and Intellectual and Developmental Disabilities Research Center (IDDR) investigator, wants to answer the question of why we sleep. Not the “because we’re tired” kind of answer but a deeper investigation of the cellular mechanisms of sleep as crucial factors in our ability to think clearly and consolidate memories.

Dr. Diering [wrote an essay](#) titled “Sleep on It” about his work and was selected as one of three finalists for the prestigious [Eppendorf & Science Prize for Neurobiology](#). Eppendorf is a biotech company founded in Germany after World War II with locations on five continents. *Science* is one of the world’s top scientific journals.

This international prize, established in 2002, encourages the work of promising young neurobiologists by providing support in the early stages of their careers. It is awarded annually for the most outstanding neurobiological research based on methods of molecular and cell biology by a young scientist of 35 years of age or younger, as described in a 1,000-word essay based on research performed during the past three years.

This year’s grand prize winner was Flavio Donato, PhD, at the Norwegian University of Science and Technology. Diering, who conducted this research while at Johns Hopkins University, was one of two other finalists, along with Viviana Gradinaru, PhD, at the California Institute of Technology.



Extended-Release Guanfacine May Reduce Oppositional and Compulsive Behaviors in Children with ASD and ADHD

Behavioral symptoms, such as hyperactivity, oppositional behavior, compulsions, anxiety, and sleep disturbance, are common reasons for taking medication in children with autism spectrum disorder (ASD). However, clinical trials investigating the effects of available medications on these symptoms specifically in children with ASD are relatively rare.

Laura Politte, MD, child and adolescent psychiatrist at the CIDD, and her colleagues (principal investigator, Dr. Larry Scahill, Emory University) recently reported on secondary findings from a randomized, placebo-controlled trial of extended-release guanfacine (GEXR) in 62 children with autism spectrum disorder and symptoms of attention deficit-hyperactivity disorder (ADHD). In a previous paper, the investigators in this multi-site study showed that GEXR significantly improved hyperactivity in 50% of the children (ages 5-12) with ASD, compared with just 9% of children in the placebo group.

The secondary analyses, published in the journal *Neuropsychopharmacology*, compared changes in parent-rated symptoms of oppositional behavior, anxiety, repetitive/ compulsive behaviors, and sleep disturbance. Thirty children with ASD and clinically significant hyperactivity were randomly assigned to receive GEXR and 32 children to receive placebo for 8 weeks. At the end of the study, children taking GEXR showed significantly more improvement in oppositional behavior and compulsive behaviors than the children taking placebo. Ratings of anxiety and sleep disturbance were not different between the groups at the end of the study, though overall ratings of anxiety were low for this group, making it difficult to detect any true effects. These analyses suggest that GEXR may be a useful medication for children with ASD and ADHD symptoms complicated by oppositional behavior, and may be modestly helpful in reducing compulsive behaviors. Further studies are needed to determine what, if any, effects GEXR may have for children with ASD and anxiety.

Triangle Business Journal's 2018 Health Care Heroes Award

Health care and business leaders gathered in March of this year at Prestonwood Country Club in Cary to honor Triangle Business Journal’s 2018 Health Care Heroes Awards winners, including our own CIDD director, Joe Piven, MD, who won an award in the innovator/researcher category. Two additional UNC School of Medicine faculty members also received awards. Anne Steiner, MD, professor of obstetrics and gynecology, won an award in the innovator/researcher category. Flavio Frohlich, PhD, associate professor of psychiatry, biomedical engineering, and cell biology and physiology; director of the Carolina Center for Neurostimulation, and member of the UNC Neuroscience Center, won in the rising star category.



Wilson Finks, An Inspiring Special Olympics Athlete

Do you know that alpine skiing is one of the Special Olympics sports? Wilson Finks, team member with CIDD's Project STIR (Steps Toward Independence and Responsibility), has decades of ski experience with the Special Olympics Program and participates in alpine skiing events each year. 2018 is already turning out to be a busy ski year for Wilson. In January, he participated in the North Carolina Alpine Skiing competition. In February, he traveled to Wintergreen for the Virginia Invitational.



Left to right: Wilson Finks with teammate, Florin Caligari



"It's fun to be able to ski and you should give it a try," encourages Wilson. "The first time I skied, I thought I was there to learn—turns out I was there to compete! The second day I got a gold medal." Wilson also participates in Special Olympics softball, track, basketball, and swimming and is an active team member of each of these sports in the North Carolina Special Olympics Program in Orange County. "I didn't participate in sports when I was in high school but when I got out and found out about Special Olympics I got interested."

Wilson is also a valued team member at Project STIR. The Project STIR program at the CIDD provides leadership for inclusion and advocacy. Wilson is a part of an inclusive team of trainers with and without developmental disabilities who lead interactive workshops and provide technical assistance to address a range of topics. Project STIR also collaborates with local, state, and national agencies and organizations to increase awareness of inclusion, self-advocacy, and self-determination.

Augmentative and Alternative Communication Training Provided to Instructors at the NC Therapeutic Riding Center



Dr. Debbie Reinhartsen and fellow speech-language pathologist, Mrs. Lynn Carswell, both augmentative and alternative communication (AAC) specialists, were invited to speak to therapeutic horseback riding instructors at the NC Therapeutic Horseback Riding Center in Mebane, NC. One of the parents of a child who participates in the program requested an in-service for the instructors because she has a son, Ayden, who uses AAC to communicate. Specifically, he uses a Pragmatic Organization Dynamic Display (PODD) communication book.

Dr. Reinhartsen and Mrs. Carswell spent a Saturday morning providing an overview of AAC and how to use aided language stimulation strategies with any communication system. Instructors were also provided with communication boards specific to horseback riding which included pages to express opinions, ask questions, complain and use quick words that could be used on the fly. Instructors learned to model the use of AAC by pointing to the pictures on the communication displays as they spoke to the riders. The instructors were enthusiastic and reportedly began using the communication boards with some of the riders almost immediately.

Left: Terri (Ayden's mother) shows Margie (Ayden's horseback riding instructor) how to use Ayden's communication system.

Rachel Greene and Robert Evans Receive CIDD Trainee Research Award

The CIDD is pleased to offer up to \$500 each for two trainees per year to assist with defraying the costs associated with presenting research related to intellectual and developmental disabilities, including lodging and travel expenses.



Clinical Psychology Graduate Student, Rachel K. Greene, MA, has been awarded the CIDD Trainee Research Award, which will provide funds for her to attend the 2018 Gatlinburg Conference on Research and Theory in Intellectual and Developmental Disabilities in San Diego, CA. At the conference, Rachel will be presenting data collected at the CIDD under the mentorship of Dr. Gabriel Dichter. Her research abstract entitled, "Social and Nonsocial Visual Outcome Prediction Errors in Autism Spectrum Disorders (ASD)" describes findings from eyetracking data which suggests individuals with ASD (age $M = 14.72$, $SD = 1.62$) show impairments in visual predictive ability compared to age-matched typically developing controls. However, this finding was not mediated by stimulus type (i.e., social vs. nonsocial), such that individuals with ASD showed this relative deficit regardless of the stimulus type. Rachel will present these results at the Gatlinburg Conference in April 2018.



LEND Advocacy Trainee, Robert Evans, has been awarded funds to attend the 2018 Southeastern Postsecondary Education Alliance Conference in Memphis TN. While at the conference, Robert will speak to the necessity of educational and inclusive opportunities to support people with IDD in becoming fully integrated members of their community. Using his recent graduation from Appalachian State University's Scholars with Diverse Abilities Program, along with his current leadership development studies at the CIDD and his plans for the future as an example, Robert will present on the importance of post-secondary education options to enable students with IDD to reach their life goals.

This CIDD Trainee Research Award is available to CIDD-affiliated graduate students, postdoctoral fellows, and other trainees actively engaged in intellectual and developmental disabilities research. The awardee must be an author on their abstract to be eligible, and preference will be given to trainees who are presenting authors. The first priority will be given to trainees who have not received this award previously and who are not receiving other support to present their research. The distance to be traveled will be considered when making decisions. Applications will be accepted on an ongoing basis, starting September 1st of each academic year. Please contact Gabriel Dichter, PhD, Director of Research at CIDD (dichter@med.unc.edu) to apply.



CIDD Collaborates on New Online Course Focused on IDD and Mental Health



CIDD partnered with the NC Division of Mental Health/Developmental Disabilities/Substance Abuse Services (DMHDDAS) and two UNC-Chapel Hill programs (the School of Social Work's Behavioral Health Springboard and Carolina Office of Online Learning) to develop an online introductory course for behavioral health and intellectual developmental disability professionals working with youth with co-occurring mental health and developmental intellectual disabilities. Nicole Cole of DMHDDAS and Lisa Lackman of UNC School of Social Work approached CIDD faculty to provide seven modules of content for the online training. CIDD contributors included Rob Christian, Jean Mankowski, Becky Pretzel, Stephanie Fox, Laura Hiruma, Laura Politte, Morgan Parlier, Jackie Lawrence, Debbie Reinhartsen and Margaret DeRamus.

BHS and COOL worked together to convert the content provided by CIDD to an online, interactive format. Online learners can choose to take any or all of the seven modules and whether to take them for free or with a small fee for continuing education credit. Click on the link below to learn more or to take the course:

<https://bhs.unc.edu/youth-mh-idd/dashboard>

the BeCure

angelman
SYNDROME
FOUNDATION walk



May 19, 2018
Early-Bird Registration:
\$25 until 2/28
After 3/1: \$35

Please join the "UNC/CIDD" team for the Angelman Syndrome Foundation (ASF) walk on Saturday, May 19, 2018 in Durham. As the location of the first of now five Angelman syndrome clinics in the country, we want to show a worthy CIDD presence! The ASF Walk raises essential funds for research to find treatments and a cure for Angelman syndrome, and provides resources and support services to families of individuals with AS.

Please use the following link to register and/or donate to our team goal:

<https://secure.e2rm.com/registrant/>



Walk Location Information

Imperial Center
4309 Emperor Blvd
Durham, NC

REGISTRATION BEGINS: 9:00 am

WALK BEGINS: 10:00 am

DISTANCE: 1/2 mile



Save-the-Date!

August 6 - 7, 2018

Chapel Hill, NC / The Carolina Inn

2018 ASF/Dup15q Alliance Research Symposium

ANGELMAN AND DUP15Q SYNDROMES: SHARED PATHWAYS TO DISCOVERY

Registration is now OPEN!

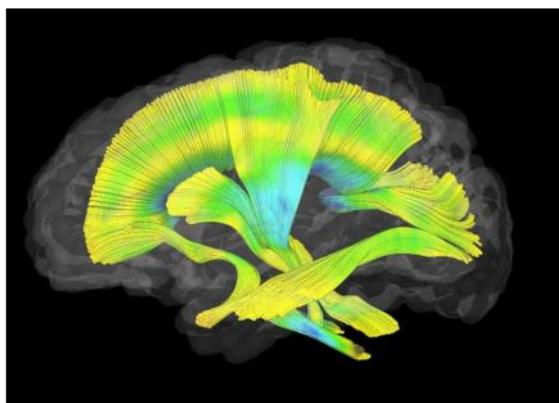
The Angelman Syndrome Foundation and Dup15q Alliance will hold their next annual scientific conference at UNC-Chapel Hill. The 2018 ASF/Dup15q Research Symposium features two full days of world-class scientific, translational and clinical presentations. The symposium allows for the sharing of unpublished work, which leads to conceptual discussions with an outstanding community of researchers and clinicians, helping accelerate therapeutic opportunities for both disorders.

[Register to Attend the Symposium](#)



Fragile X Imaging Study Reveals Differences in Infant Brains

UNC School of Medicine researchers used MRIs and computer models to show that babies who develop the neurodevelopmental condition fragile X syndrome have less white matter circuitry compared to other babies. About one-third of people with fragile X meet the diagnostic criteria for autism.



This image shows all of the white matter fiber tracts investigated in this study. (courtesy of Dr. Meghan Swanson)

For the first time, CIDD investigators at the UNC School of Medicine have used MRIs to show that babies with the neurodevelopmental condition fragile X syndrome had less-developed white matter compared to infants that did not develop the condition. Imaging various sections of white matter from different angles can help researchers focus on the underlying brain circuitry important for proper neuron communication.

The study, published in *JAMA Psychiatry*, shows that there are brain differences related to the neurodevelopmental disorder established well before a diagnosis is typically made at age three or later.

"It's our hope that earlier diagnosis and intervention will help children with fragile X and their families," said co-first author Meghan Swanson, PhD, postdoctoral research fellow at the CIDD. "We also hope that this knowledge might inform drug development research."

So far, drug clinical trials have failed to demonstrate change in treatment targets in individuals with fragile X. One of the challenges

has been identifying good treatment outcome measures or biomarkers that show response to intervention.

Fragile X syndrome is a genetic disorder and the most common inherited cause of intellectual disability in males. Symptoms include intellectual disabilities, problems with social interaction, delayed speech, hyperactivity, repetitive behaviors and speech. About 10 percent of people with fragile X experience seizures. About one-third of people with fragile X meet the diagnostic criteria for autism spectrum disorder.

"One of the exciting things about our findings is that the white matter differences we observe could be used as an objective marker for treatment effectiveness," said co-senior author Heather C. Hazlett, PhD, assistant professor of psychiatry at the CIDD.

For this study, Swanson, Hazlett, and colleagues imaged the brains of 27 infants who went on to be diagnosed with fragile X and 73 who did not develop the condition. The researchers focused on 19 white matter fiber tracts in the brain. Fiber tracts are bundles of myelinated axons – the long parts of neurons that extend across the brain or throughout the nervous system. Think of bundles of cables laid across the brain. These bundles of axons connect various parts of the brain so that neurons can rapidly communicate with each other. This communication is essential, especially for proper neurodevelopment during childhood.

Imaging and analytical analysis showed significant differences in the development of 12 of 19 fiber tracts in babies with fragile X from as early as six months of age. The babies who wound up being diagnosed with fragile X had significantly less-developed fiber tracts in various parts of the brain.

"These results substantiate what other researchers have shown in rodents – the essential role of fragile X gene expression on early development of white matter in babies," said co-first author Jason Wolff, PhD, former postdoctoral fellow at UNC-Chapel Hill and now assistant professor of educational psychology at the University of Minnesota. "Our work highlights that white matter circuitry is a potentially promising and measurable target for early intervention. However, achieving the goal of infant intervention for fragile X would likely require expanded newborn screening efforts."

Other authors are Mark Shen, PhD, Martin Styner, PhD, and Joseph Piven, MD, of the University of North Carolina at Chapel Hill; Annette Estes, PhD, of the University of Washington; Guido Gerig, PhD, of New York University; and Robert McKinstry, MD, PhD, and Kelly Botteron, MD, of Washington University in St. Louis.

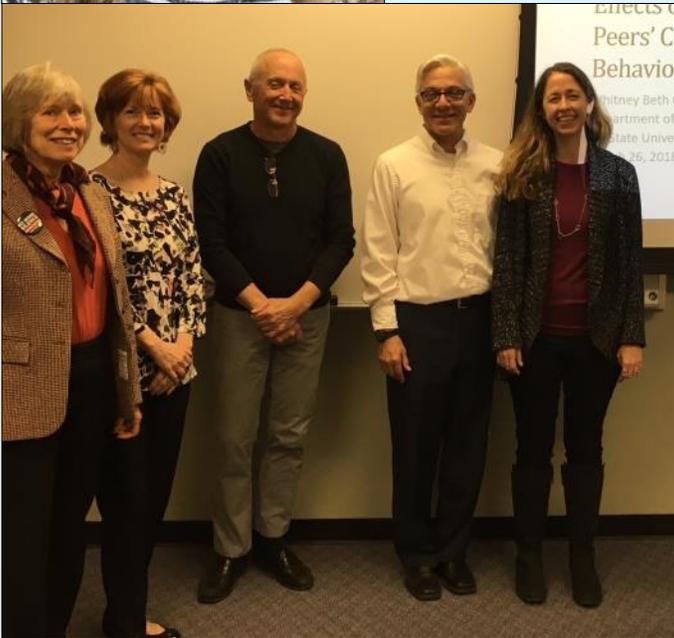
Funding was provided by the National Institutes of Health and the Simons Foundation. This study, which used data collected from 2008 to 2016, would have been impossible without the dedication to research from families who had another older child already diagnosed with fragile X syndrome.

Successfully Defended Dissertations

Congratulations to Rachel Earl, Whitney Griffin, and Jackie Lawrence for the successful defense of their dissertations.



Rachel Earl successfully defended her dissertation, "DYRK1A haploinsufficiency as a subtype of ASD: Phenotypic presentation and the role of parental phenotype in accounting for variability in individuals with ASD and disruptive DYRK1A mutations" at the University of Washington in October 2017. This study explored the clinical presentation of a rare disruptive single gene mutation, DYRK1A, a high-confidence ASD risk gene. Results confirmed a core clinical phenotype for DYRK1A disruptions, characterized by microcephaly, intellectual disability, speech and motor difficulties, vision impairments, and feeding difficulties. This set of features occurred in combination at a rate that was distinct from those with idiopathic ASD. Moreover, quantitative characterization of DYRK1A haploinsufficiency illuminated clinical variability between affected individuals, which may be, in part, due to familial genetic background. Rachel's dissertation research was recently published in *Molecular Autism*. Rachel will graduate in June 2018 with her PhD in School Psychology from the University of Washington. Following the completion of her predoctoral internship at CIDD, Rachel is looking forward to returning to the Pacific Northwest to complete her postdoctoral fellowship at Seattle Children's Hospital Autism Center.



Whitney Griffin and her dissertation committee (post-defense). Pictured above from left to right: Dr. Susan Osborne, Dr. Mary Haskett, Dr. Thomas Hess, Dr. Scott Stage (committee chair), and Whitney Griffin

Whitney Griffin successfully defended her dissertation, "Effects of a Brief Psychoeducational Intervention on Peers' Cognitions, Emotional Reactions, and Behavioral Intentions towards Students with ASD" in March, 2018. She found that middle school-age participants were more willing to interact with a typically developing student and a student with more severe ASD as compared to a student with high functioning ASD (as depicted in video vignettes). Participants also reported higher ratings of cognitive attributions (i.e., statements of blame/responsibility for behavior), higher ratings on an anger scale, and lower ratings of sympathy towards the student with high functioning ASD as compared to the student with moderate to severe ASD. The intervention specifically targeting ASD was not uniquely effective, but results suggest that either an ASD-specific educational intervention or broad-based character education may be helpful for mitigating negative peer perceptions towards students with high functioning ASD. After completing her psychology internship at CIDD, Whitney will graduate in May from NC State University with her PhD in School Psychology. She looks forward to returning to the CIDD next year as a postdoctoral fellow and education specialist as well as working in a postdoctoral role with the Psychoeducational Clinic at NC State University.



Jackie Lawrence successfully defended her dissertation, "Self-Injurious Behavior and Comorbidities in Children with Autism Spectrum Disorder" in May 2017. The purpose of the study was to examine relationships among factors most commonly associated with self-injury in autism spectrum disorders (ASD) in greater depth. Predictor variables included age, gender, the Adaptive Behavior Composite, sensory processing, aggression, stereotypies, irritability, adaptive skills (communication, daily living skills, socialization), and medical conditions (gastrointestinal disorders, seizure disorders, vitamin D deficiencies). Findings indicated that various factors correlate with self-injurious behavior (SIB) in ASD, including aggression, stereotypies, irritability, the Adaptive Behavior Composite, communication, daily living skills, and socialization. Age, irritability, and the Adaptive Behavior Composite were found to significantly predict SIB. After completing her psychology internship at the CIDD, Jackie will graduate in May 2018 from UNC Chapel Hill with her PhD in School Psychology. She is excited to transition to the Duke Center for Autism & Brain Development in September 2018 as a postdoctoral fellow.

Announcing Our 2018 Social Smarts Summer Camps



This camp program, based on Michelle Garcia Winner's Social Thinking® model, will provide structured practice of social thinking skills in a positive, supportive and kid-friendly environment. Social thinking ideas, language, and strategies will be woven into the entire camp experience. Through group activities, play, drama, and individual instruction campers will develop self-awareness, self-monitoring, self-regulation, and flexible social thinking skills. These tools have proven to be effective in improving social functioning and behavior at home, school, and in the community as well as building self-confidence and self-esteem.

The CIDD will hold two sessions of camp this year:

The first session of camp will take place June 18-22 (9am -12pm) and will be for children ages 5-7 (some flexibility with ages, depending on rest of group). This week of camp will focus on the foundational Social Thinking concepts, using the *We Thinkers Volume 1 Social Explorers* curriculum (formerly *The Incredible Flexible You*) and *Zones of Regulation*.

The second session of camp will take place June 25-29 (9am -12pm) and will be for children ages 6-8 (some flexibility with ages, depending on rest of group), who have either attended Social Smarts camp previously or have prior experience with the foundational Social Thinking concepts covered in the first session of the camp. This week of camp will build on the foundational Social Thinking concepts used in session 1, focusing on the advanced topics covered in the *We Thinkers Volume 2 Social Problem Solvers* and *Zones of Regulation*. A camper is welcome to attend both weeks of camp.

For more information on the camp, please contact Margaret DeRamus at margaret.deramus@cidd.unc.edu by Friday, May 4, 2018.

CIDD Community Talk Series

The CIDD hosts a series of talks to share information about recent advances in developmental disabilities. These sessions are a great opportunity for parents, teachers, professionals, and others to learn more about specific developmental disabilities topics. All talks are free, and everyone is welcome. Join us for our next talk!



Wednesday, May 9

6:30 PM to 8:00 PM

CIDD Castelloe Conference Room 101

Ann Palmer - LEND Family Faculty

Morgan Parlier, LCSW - Social Work Faculty - CIDD

"Disclosure: To Tell or Not to Tell"



One of the most complex decisions faced by parents/caregivers and by individuals with I/DD is whether to disclose disability status and/or differences. This presentation will look at disclosing a diagnosis to others in the community as well as to the child/individual. The speakers will include factors involved in the decision-making process, benefits and challenges, and some strategies for effective disclosure.

For more information on the Community Talk Series, contact Dr. Debbie Reinhartsen Debbie.Reinhartsen@cidd.unc.edu or 919-966-4138 or visit our website:

<http://www.cidd.unc.edu/Education/CommunityTalk/2018CommunityTalkSeries.aspx>

LEND Audiology Trainees Receive Outstanding Poster Award at National Conference



LEND Audiology Trainees, from left to right, Ashley McMillen, Megan Bartoshuk, Crystal Smaldone, and Stephanie Berry.

Four first-year LEND trainees in UNC's Doctor of Audiology (AuD) program were honored in March at the Annual Early Hearing Detection and Intervention (EHDI) meeting in Denver, CO, for a poster presentation entitled: "Screening, Diagnosis, and Management of Hearing Loss in Children with Significant Cognitive Disabilities," which was selected for an 'Outstanding Poster Award' in the student category. The project is focused on children with the most severe physical and/or cognitive disabilities whose conditions can overshadow a hearing loss. As a result, children who could benefit from hearing aids or cochlear implants may be denied or delayed in their access to sound and auditory learning. Dr. Jack Roush, Director of NC LEND and one of the project mentors, notes: "These four students, in the first year of their four-year graduate program, have demonstrated a remarkable a commitment to improving audiology services to the most challenging of our pediatric populations. We are very proud of the work they are doing." The project was initiated by faculty from the Center for Literacy and Disability Studies in the Department of Allied Health Sciences, Nancy Quick, PhD and Karen Erickson, PhD, working in collaboration with audiology faculty from the Division of Speech and Hearing Sciences, Martha Mundy, AuD, and Dr. Roush.

The CIDD and the UNC Neuroscience Center Co-Host the Next Monthly INVESTIGATOR FORUM



"How Immune Cells Sculpt Brain Circuitry in Health & Disease"

Beth Stevens, PhD

Associate Professor of Neurology
Boston Children's Hospital
Harvard University

Beth Stevens received her PhD in Neuroscience in 2003 from the University of Maryland, College Park and completed her postdoctoral fellowship at the Stanford University School of Medicine in 2008. She is a recipient of several awards including the Smith Family Award for Excellence in Biomedical Research, Dana Foundation Award (Brain and Immunoimaging), Ellison Medical Foundation New Scholar in Aging award, John Merck Scholar Program, and MacArthur Fellows Program.

WHEN:

Thursday, April 19th
12:30 - 1:30 PM

WHERE:

UNC-CHAPEL HILL Campus
Bioinformatics Building
Room 1131
130 Mason Farm Road
Chapel Hill, NC 27599



 **LIGHT IT UP BLUE**
Shine a Light on Autism

CIDD Together with UNC TEACCH Autism Program
“Light It Up Blue”
for
2018 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!

A gift to the Carolina Institute for Developmental Disabilities is an investment in the lives of thousands and in the future of our communities. Join us by giving today. To make a donation by credit card, please visit the Medical Foundation of North Carolina's gifting page and choose "Carolina Institute for Developmental Disabilities:" [Click Here.](#)

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info@cidd.unc.edu

A text only version of the newsletter in Word is available.

Newsletter Editor—Keath Low