THE UNIVERSITY of NORTH CAROLINA at CHAPEL HILL

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Inside the Institute

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Drs. Kelly Caravella, Dea Garic, and Rebecca Grzadzinski Receive Research Career Development Awards

Three CIDD junior faculty, jointly, obtained an unusual milestone – all three, Drs. Kelly Caravella, Dea Garic, and Rebecca Grzadzinski, received NIH Research Career Development Awards from the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) earlier this year to study neurodevelopmental disorders.

Dr. Caravella (pictured on the right) is studying factors that contribute to health care disparities in Black toddlers accessing an early autism intervention study.

Dr. Garic (center) is employing MRI to study the impact of physiological differences in cerebrospinal fluid dynamics on early development in young children with Down Syndrome, autism and Fragile X Syndrome.

And, Dr. Grzadzinski (left) is examining atypical arousal patterns, as indexed by pupillary responses to sensory stimuli, in young children with Down Syndrome, with translational research links to the study of a similar paradigm in rodent models.

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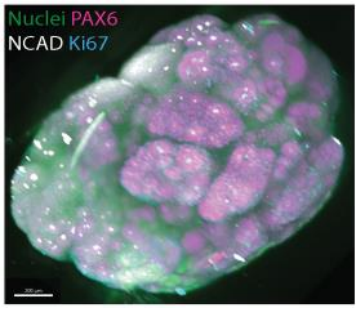
Generating Brain Organoids to Model Brain Development in Autism

A new project led by the lab of Jason Stein, aims to understand the cellular and molecular basis leading to brain overgrowth in individuals with autism, building on the unique resources of the UNC-led, NIH-funded, Infant Brain Imaging Study (IBIS) Network. "We think that changes in the way the brain forms, during prenatal development, produce more cells and lead to bigger brains in those individuals that go on to develop autism," says Stein. Stein's study uses participants from IBIS, led by Joe Piven at the CIDD, which found that, on average individuals with autism spectrum disorder have increased brain growth in the latter part of the first and second years of life that leads to having enlarged brain volumes in their second year of life.

Stein's study employs cutting edge methods to model prenatal brain development in participants from IBIS who are enrolled at 6 months of age and followed forward with serial brain MRI.



A picture of a human cortical organoid, somewhat smaller than a pea.

Induced pluripotent stem cells or iPSCs are a way of changing (or reprogramming) blood cells taken from study subjects during a routine blood draw, "to go back in time" modeling what might have happened in the brain development in the embryo from that individual. From those iPSCs, we can add certain compounds to differentiate them to be little balls of cells that are like the prenatal brain, called cortical organoids.

Since 2019, we've been asking IBIS participants to participate in this study. We've had over 110 individuals participate so far with blood draws. We recently received a $4.6M National Institutes of Health (NIH) grant to conduct this work. Cortical organoids from IBIS participants form the expected cell types present in the prenatal brain and function in some of the ways we expect, like forming structures that are present in the developing human brain. These models of the brain in a dish will help us understand the brain development in autism, and provide important insights into how alterations in brain development can lead to differences in individual behavior.

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

CIDD Welcomes New Faculty

The CIDD welcomes **Kelly Caravella, PhD**, to her new role at the CIDD as a Research Assistant Professor. Following her doctoral training at the University of South Carolina in Clinical-Community Psychology, Dr. Caravella completed her internship and clinical postdoctoral training at the CIDD, specializing in intellectual and developmental disabilities. After obtaining licensure as a psychologist, she was accepted as a postdoctoral fellow in the CIDD's T32 Postdoctoral Research Training Program. Following three years as a T23 fellow, Dr. Caravella was selected as a scholar for the NC Translational and Clinical Sciences Institute (NC TraCS) K12 program. Dr. Caravella's project will focus on testing the effectiveness of a family navigation intervention in expediting access to autism specific intervention for Black toddlers with a new diagnosis of ASD under the age of 3. Through this award, Dr. Caravella will receive additional focused training in health equity research, implementation science, intervention study design and mixed-methods research. She aims to develop a program of research that advances health equity and improves functional outcomes for children with neurodevelopmental disabilities from historically marginalized groups.

Dea Garic, PhD, also joins the CIDD faculty as a Research Assistant Professor. Dr. Garic completed her doctoral training at Florida International University in Psychology, with a dual focus on developmental science and cognitive neuroscience. She joined the CIDD in July 2020 as a Postdoctoral Fellow in the T32 Training in Neurodevelopmental Disorders Program, co-mentored by Drs. Joseph Piven and Mark Shen. Shortly after competing her T32 training, Dr. Garic was granted a 5-year K01 Career Development Award, which aims to elucidate and contrast trajectories of CSF characteristics in Down Syndrome (DS) and related disorders (autism spectrum disorder and Fragile X syndrome) across the first two years of life. Further, her work aims to determine the relationships between CSF physiology and later neural and clinical features of DS. Given that 50% of children with DS will go on to develop early-onset Alzheimer's, CSF physiology can serve as a mechanistic pathway to aberrant brain and behavioral development and has the potential to guide the design of targeted therapeutics for early intervention.

Anne Harris, PhD, joins the CIDD faculty as a Clinical Assistant Professor. Dr. Harris completed her psychology internship and two years of psychology postdoctoral fellowship with the CIDD. She completed her doctoral degree in psychology and neuroscience at Duke University. Dr. Harris brings a wealth of experience, knowledge and expertise in working with individuals with a variety of intellectual and developmental disabilities and their families. She has also worked previously at UNC on multiple IDD-related research studies including ones focused on Fragile X Syndrome. Her current areas of interest focus on eating and feeding differences as well as the relationship between autonomic nervous system functioning and mental health. Dr. Harris is conversational in Spanish and will be a great asset in our efforts to support families for whom English is not their primary language. She will be involved in multiple clinical efforts, including the School-age Team, and she will participate on several contracts such as Complex Care and NC-PAL. Dr. Harris will also be partnering with the Department of Pediatrics to provide psychological services for some of their patients on a regular basis.

Congratulations to Sue Porr on her Retirement

We want to take this opportunity to say thank you to Sue Porr, MEd, MS, OTR/L, for her many years of service at the CIDD. As the CIDD's longstanding contract with DPI to provide training and TA to public school teams on assistive technology comes to an end, Ms. Porr will be leaving the CIDD. Although she retired from the public schools a few years ago, we have been fortunate to have her continue to work with us. Ms. Porr has been at the CIDD for many years, first serving as the OT on clinical teams, then teaching/lecturing and providing occupational therapy services on multiple contracts and grants. She is an exceptional clinician who brings energy, enthusiasm, and positivity to every project and has a wealth of knowledge and ideas to support persons with disabilities and their families. Sue is always stepping up to support colleagues, meet with and mentor students, and connect families with resources across the state. Her positive spirit and love for her work and life is apparent in everything she does. We wish her a very happy retirement!

Whole Community Connection Awards Rural Community-Academic Partnerships

Whole Community Connection (WCC) supports cohorts of leaders to advance health equity in rural North Carolina by increasing local power to focus on priorities by and at the community level and co-creating a model of relationship centered engagement.

Increasing sexual health equity and reducing sexual violence within the IDD community requires community partnerships. CIDD's Margaret DeRamus, MS, CCC-SLP, and Morgan Parlier, MSW, LCSW, are leading the effort to reduce sexual violence and increase sexual health equity in the intellectual/developmental disability (I/DD) community in Robeson County in partnership with Amy Perry, Resource Specialist for Robeson and surrounding counties, with the Autism Society of North Carolina (ASNC), and local Robeson County community member, Virginia Locklear, Director of the Rape Crisis Center of Robeson County (RCCRC).

Whole Community Connection Champion Team: Morgan Parlier, Margaret DeRamus, Virginia Locklear, and Amy Perry.

This community partnership with ASNC and the RCCRC is providing community trainings for professionals, families and self-advocates on best practices for providing sexual health education to individuals with I/DD. In addition, they are providing professional guidance on how best to promote sexual health equity and provide trauma informed care to members of the I/DD community.

The partnership is also developing a training program for sexual assault response teams on how best to support survivors with IDD. Both trainings will be advertised and offered for free to community stakeholders: self-advocates, family advocates, sexual assault response team (SART) members, healthcare providers, law enforcement, educators, advocacy organizations, etc. Both trainings will be archived and available for view online. ASNC will provide Spanish translation of the community and professional trainings. They anticipate an increased capacity to provide preventive education, equitable sexual health care, and greater awareness of the need for continued efforts to address this epidemic of sexual violence impacting the I/DD community across the state.

HEELS 2 Transition

Higher Education, Employment, Living Success

Supporting individuals with intellectual disabilities transitioning to adulthood

H2T is an umbrella organization that houses HEELS UP, HEELS Bridge, and HEELS Prep. H2T supports transition-aged individuals (18-26) with I/DD toward a self-determined adult life. HEELS 2 Transition, UNC's summer transition and postsecondary education programming, continued into its 5th year with more face-to-face experiences and new residential opportunities. HEELS UP is the first-ever inclusive postsecondary program at UNC. It wrapped up its third summer with 7 students, each completing a UNC Summer School II course offering (ranging from Geography to Arts and Fitness classes) and earning a certificate of completion. In addition to completing class assignments, UP students learn about college access and readiness. Two of the 7 students also lived on campus in apartments with a peer support and all students participated in weekly Community Dinners at the apartments, completing all steps of the meal planning, preparation, eating and clean up.

Another program addition is HEELS Week Away which also takes place on campus in a residence hall. There were 14 participants whose experiences included doing laundry, meal planning and cooking, and participating in daily skill development activities. Several trips were taken to various campus sites and activities. HEELS Prep-Hybrid, a life skills based series of classes combined in-person and online program offerings from the past 4 years into a new 4-week hybrid program to a cohort of 11 participants. In addition to learning about goal setting and life skills like cooking and cleaning, participants work on social planning and personal wellness, and had the opportunity to learn about sexual health and violence prevention this year.

Total numbers of youth that participated this summer was 31. The programs continue to recruit and diversify with 10 participants identifying as non-white. Individuals with disabilities also served in leadership roles as mentors and supports in paid positions. H2T also provided mentorship and training in strengths-based, person-centered approaches to 25 graduate student coaches, and involved 9 undergraduate peer supports.

H2T is an interdisciplinary collaboration between CIDD, TEACCH, UNC's School of Education, Division of Occupational Therapy, Division of Clinical Rehabilitation and Mental Health Counseling, and regional non-profit Fullpower North Carolina. For more information, see the H2T website: https://www.med.unc.edu/ahs/outreach/heels2transition/

HEELS UP

HEELS UP students at Kenan Stadium. Pictured left to right are Elianna Horner, Chadi Halim, and Braden Wilkinson.

Cynthia Harris: Advocacy in the Disability Community

Cynthia Harris recently completed her work as Vocational Rehabilitation Intern for the CIDD. Learn more about Ms. Harris as she shares her experiences and training in disability advocacy.

Cynthia Harris and Kelly Friedlander

My name is Cynthia Harris, I am a former Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Self-Advocate Trainee. I am a single, African American female who is a three-year survivor of Traumatic Brain Injury. I am a mother of two girls, Moriah and Laniya (pre-teen and teen age). I am a soon to be grandmother of a little girl named True. I am a Certified Peer Support Specialist who wants someone to give me a chance.

I was a daycare teacher for sixteen years. Once I became disabled, I decided that working in that field was no longer my passion. I started taking advocacy classes in 2022. I fell in love with the field after being involved in the Ability Leadership Project of North Carolina (ALP-NC) with Kelly Friedlander, MSW, MPA, of the Community Bridges Consulting Group.

ALP-NC is a leadership training program for adults with intellectual and developmental disabilities (I/DD), family members of children and adults with I/DD, or professionals in the I/DD field. ALP-NC prepares individuals to be effective local, state, and federal advocates. ALP-NC helps you be an advocate and leader for the disability community, working together to create a more accessible world.

After completing the ALP-NC program, I took a Peer Support Specialist class with NC-H.O.P.E. and received my certificate of completion and my state certification as a Peer Support Specialist. Next, I signed up for and completed the Leadership Education in Neurodevelopmental Disorders (LEND) at UNC–Chapel Hill. I am excited to be an advanced Trainee this year.

Over the summer, I had an opportunity to work as a Vocational Rehabilitation Intern for the Carolina Institute for Developmental Disabilities at UNC–Chapel Hill. My first role was working with the HEELS UP Inclusive Post-Secondary Education program. I served as a program assistant and an ally to the staff, students, and coaches. I assisted with the group dinners and joined in social outings on the bus and to Franklin Street. Once the summer program ended, I was able to work in the office assisting the Director of Advocacy and Inclusion, Anna Ward, and other faculty and staff. I have had the chance to help with various tasks, like sorting files, typing and research.

I am very passionate about advocacy work and human rights. I am ready and willing to be educated by the leaders in the advocacy field. My mentors are Kelly Friedlander and Anna Ward. I am very grateful for these two women for taking me under their wings!

The Carolina Institute for Developmental Disabilities T32 Post-Doctoral Research Training Program Announces New Directors and the New Trainees

It gives us great pleasure to announce that, as of July 1, 2023, Dr. Mark Shen became the Associate Director of the CIDD T32 Post-Doctoral Research Training Program on Neurodevelopmental Disorders. Dr. Shen joins Dr. Ben Philpot, who became Director of the Program. Previous Director, Dr. Joe Piven, stepped down after successfully directing this training program for over 20 years. Funded by the NIH, the CIDD T32 program has trained over 60 post-doctoral trainees to date. It was one of the first programs in the U.S. to focus on bringing together multi-disciplinary trainees to accelerate translational research on neurodevelopmental disorders.

Drs. Shen and Philpot will work with a talented group of six post-doctoral research fellows in our training program on neurodevelopmental disorders research: Crisma Emmanuel, Austin Ferguson, Jiseok Lee, Tyler McFayden, Jieun (Esther) Park, and Joshua Rutsohn. We are thrilled to have these talented postdoctoral fellows in our interdisciplinary program, and we would like to introduce the fellows and the T32 Co-Directors to the CIDD community.

Dr. Mark Shen is a developmental neuroscientist, Assistant Professor of Psychiatry, and member of the Neuroscience Center and CIDD. He is also the Co-Director of the CIDD Clinical Trials Program with Dr. Jamie Capal. Dr. Shen earned his PhD from the University of California-Davis MIND Institute, and completed the CIDD T32 postdoctoral fellowship with Drs. Joe Piven, Heather Hazlett, and Martin Styner. Dr. Shen has pioneered research on the role of aberrant cerebrospinal fluid physiology in the pathogenesis of autism and other neurodevelopmental disorders. His research identifying early brain markers of developmental disabilities has received widespread recognition, with his research articles cited in numerous prestigious annual top ten lists. As a former T32 fellow and then T32 faculty mentor since 2017, Dr. Shen is the ideal fit to co-lead our T32 training program, and we are extremely pleased that he will serve as the Associate Director.

Dr. Ben Philpot has been the Associate Director of the CIDD T32 postdoctoral training program since 2009, and he is excited to assume the role of Director of the program. Dr. Philpot is a Kenan Distinguished Professor in the Department of Cell Biology & Physiology. He earned his Ph.D. at the University of Virginia and performed a postdoctoral fellowship in the laboratory of Dr. Mark Bear at M.I.T. and Brown University. He is the Associate Director of the UNC Neuroscience Center and a member of the Carolina Institute for Developmental Disabilities. Dr. Philpot seeks to understand the pathophysiology underlying monogenic neurodevelopmental disorders, and he is developing small molecule and gene therapies to treat these disorders. His research focuses on early-stage development of treatments for Pitt-Hopkins, Dup15q, and Angelman syndromes. Dr. Philpot has >100 peer-reviewed scientific publications and has won multiple awards for his work in neurodevelopmental disorders.

2023 T32 Postdoctoral Trainees in Neurodevelopmental Disorders

Dr. Crisma Emmanuel received her PhD in Nursing from UNC at Chapel Hill working with Dr. Hudson Santos. Her research examines socio-environmental factors that affect child development and health among children at high risk of developing a neurodevelopmental disorder. She is currently a postdoctoral associate at UNC working with Dr. Michael O'Shea on examining environmental factors that affect the health and development of extremely preterm born children. As a T32 fellow at the CIDD, Dr. Emmanuel will evaluate biosocial factors affecting the well-being of children with a neurodevelopmental disorder.

Continued on next page

2023 T32 Postdoctoral Trainees in Neurodevelopmental Disorders *continued*

Dr. Austin Ferguson received their PhD in Mathematics from the University of North Carolina at Chapel Hill working with Dr. Peter Mucha. Dr. Ferguson's graduate work was centered around applied math, with a focus on network analysis/graph theory and data science, working on applications with genomics data, EEG, fMRI brain scans, and social networks. As a T32 Fellow at the CIDD, Dr. Ferguson will be working with the IBIS Network, jointly at UNC with Dr. Piven's lab and with Dr. John Pruett at Washington University to develop novel methods of analyzing functional connectivity fMRI data.

Dr. Jiseok Lee received her PhD in Biological Sciences from Korea Advanced Institute of Science and Technology (KAIST) working with Dr. Eunjoon Kim. Her research examines molecular, physiological, and behavioral alterations in autism model Shank3-mutant mice. As a UNC CIDD T32 Fellow, Dr. Lee will work with Dr. Hyejung Won to examine transcriptomic changes in mouse brain cells after CRISPR perturbation of genes linked to autism-associated genetic variants. Her ultimate goal is to decipher gene networks involved in autism in a cell type-specific manner.

Dr. Tyler McFayden received her PhD in Clinical and Developmental Psychology from Virginia Tech working with Dr. Thomas Ollendick. Her research examines brain and behavioral metrics of social communication in infancy, youth with neurodevelopmental disorders, and individuals who are Deaf/Hard of Hearing. As a UNC CIDD T32 Fellow, Dr. McFayden will continue to work with Dr. Clare Harrop and Dr. Michael O'Shea, in year two of the fellowship, to examine developmental trajectories of social communication in autistic youth and preterm infants. The ultimate goal of her program of research is to improve our multi-modal systems of early language detection and communication interventions for autistic youth.

Dr. Jieun (Esther) Park received her PhD in Cell Biology from Duke University with Dr. Michel Bagnat. Her PhD work focused on the development of specialized intestinal cells important for protein absorption. For her postdoc, she decided to switch gears and focus on neuroscience with the eventual goal to better understand the connection of brain and gut development. As a UNC CIDD T32 fellow, Dr. Park will work with Dr. Jason Stein to investigate the underlying molecular mechanisms leading to cortical surface area expansion in autistic individuals early in life using brain organoids as a model system.

Dr. Joshua Rutsohn received his DrPH in biostatistics from the Gillings School of Public Health at UNC-Chapel Hill under the guidance of Dr. Young Truong. His research encompasses the estimation of latent variables from longitudinal and time-series data. As a UNC CIDD T32 Fellow, Dr. Rutsohn will work with Drs. Young Truong and José Rodriguez-Romaguera to develop arousal metrics from biometric signal data sampled from translational models. His research will attempt to find ways to model heterogeneity inherent to neurodevelopmental data.

CIDD at the Association of University Centers on Disabilities Annual Conference

Pictured left to right: Jean Mankowski, Anna Ward, Brianne Tomaszewski (TEACCH), and Kenneth Kelty

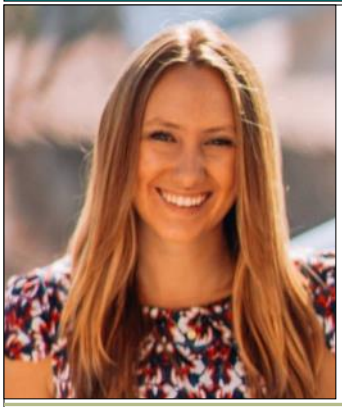
NC LEND Family Faculty, Djenne-amal Morris (pictured above far right), along with Arkansas LEND Faculty Elizabeth Cleveland (pictured center) and Paige Jones-Brookes (pictured far left), presented at the AUCD Conference. Their session, "Cultural Reflections in Allyship: Affirming Practices to Enhance Leadership," focused on strengthening the affirming and inclusive practices in disability leaders.

CIDD Disability Advocate, Kenneth Kelty, and Dr. Brianne Tomaszewski, UNC TEACCH Autism Program, co-presented on the Work Together NC Initiative at the AUCD Conference. They gave a reflection on the progress of the Work Together NC project and community partners to collectively improve transition experiences for individuals with I/DD and family members, service providers, educators and employers.

CIDD Trainee Research Award Recipients

Hayden Loeb, BS, a LEND trainee representing postsecondary education and research assistant with UNC TEACCH, has been awarded the 2023 CIDD Trainee Research Award. This award will provide funds for her to attend the 56th Gatlinburg Conference on Research and Theory in Intellectual and Developmental Disabilities in Kansas City, Missouri in April 2024. The poster she will present outlines preliminary data analyses for two ongoing studies that utilize GPS data to measure community participation for young adults with IDD. The studies also included measures for quality of life, revealing that a larger perceived effect of disability on daily life predicted a lower quality of life. Additionally, it was found that participants living with paid caregivers were not only significantly more likely to report greater overall quality of life, but also specifically greater psychological well-being. Finally, findings suggested moderate positive correlations between quality of life and community participation, especially when community participation was measured as the number of unique locations visited in a one week period.

Maria Novak, MA, a LEND trainee representing the UNC School Psychology PhD program and research assistant with the CIDD, has been awarded the 2023 CIDD Trainee Research Award. This award will provide funds for her to attend the American Cleft Palate Association 81st Annual Meeting in Denver, Colorado in April 2024. Her oral presentation outlines preliminary data analyses examining social and emotional complications among adolescents with non-syndromic cleft lip/palate (nsCL/P) more than two years since the onset of the COVID-19 pandemic. The study involved a retrospective chart review of patients seen for their standard initial or follow-up visits in a multi-disciplinary craniofacial clinic. Rates of endorsed anxiety and/or depression and parent or self-report of bullying from peers in the past year were obtained through a mental health intake questionnaire then verified in a semi-structured interview. While under-reporting of mental health and psychosocial concerns can be problematic during multidisciplinary team visits, the rates of anxiety, depression, and teasing/bullying in this sample were similar to prior estimates in nsCL/P samples from pre-pandemic research. Future research should aim to compare post-pandemic social and emotional concerns through both parent and self-report survey data to further identify newer contributions to negative self-perceptions and reduced self-esteem (e.g., amount of social media use, satisfaction with speech and appearance, perceived amount of support from caregivers, family stress).



Claire Klein, MA, a doctoral student in Clinical Psychology at UNC Chapel Hill and 2022-2023 LEND Fellow, was awarded the CIDD Trainee Research Award in 2022. This award provided funding to present the Feasibility of the Higher Education, Employment, Living Success (HEELS) Prep Program for Transition-Aged Adults with Intellectual Disability, led by Dr. Brianne Tomaszewski, Dr. Dara Chan, and the HEELS2Transition team, at the 2023 Gatlinburg Conference in Kansas City, MO. Claire presented during a session on postsecondary experiences of adults with intellectual and developmental disabilities, chaired by Dr. Brianne Tomaszewski. This session highlighted a growing interest in understanding the experiences of adults with IDD and learning how to best support adults with IDD in reaching their goals in adulthood. Claire's conference presentation demonstrated the initial feasibility and efficacy of the HEELS Prep Program and increases in student confidence across the program curriculum, including independent living skills, self-management and goal setting, and career exploration.

Chavely Gonzalez Ramirez, MS, student in Speech Language Pathology at UNC School of Medicine, was awarded the CIDD Trainee Research Award in 2022. Ms. Gonzalez Ramirez had been working in Dr. Philpot's Lab to study Pitt-Hopkins and Angelman Syndrome, two neurodevelopmental disorders resulting in profound communication impairments. This award provided Ms. Gonzalez Ramirez funds to present her research findings in the Neuroscience Conference which took place in San Diego, California. Her poster presentation was on the "Regional and cellular organization of the intellectual disability and schizophrenia-associated transcription factor TCF4 in the developing rhesus macaque brain." The results indicated that the TCF4 expression in primates is more complex than in the rodent model. This information is key for eventual therapeutic interventions. Ms. Gonzalez Ramirez is grateful to Dr. Philpot's Lab and Ms. Margaret DeRamus, her LEND mentor.

NC-LEND 2023-2024 Trainees and Fellows

Ezequiel Bautista is a music therapist at UNC Hospitals. He has music therapy experience in outpatient, pediatric medical, and immigration settings and his practice pulls from anti-oppressive approaches to therapy and community healing in music. He grew up on the border between Texas and México and is active in writing about Borderlands theory in music therapy research.

Sydni Beeley is a first-year genetic counseling graduate student at UNC-Greensboro. Her clinical and research interests focus on patient empowerment, family dynamics, and disability intersectionality. In her career, Beely hopes to support those with genetic conditions and disabilities as a pediatric or metabolic genetic counselor.

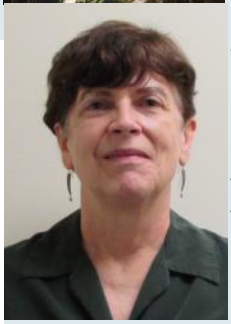
Michael Bell is a LEND self-advocate. He has a podcast with his two autistic friends called Team Autismo. Bell's other interests include blacksmithing, gardening, and table top role-playing games.

Shalina Brady is a graduate student in the UNC School of Social Work. She is dedicated to empowering individuals with intellectual/developmental disabilities and increasing equitable access to educational, recreational, and social opportunities. Brady has a particular interest in addressing the needs of clients who hold intersecting identities within the context of their families and communities.

Hannah Bryan is a graduate student in the School of Social Work at UNC and is a member of LEND as a family representative. She is interning this year at the CIDD in the Advocacy and Inclusion unit. Bryan is passionate about advocacy work with the IDD community and is interested in working alongside Urban Planning to advocate for under-resourced and gentrified communities.

Tess Clark is a 3rd year Doctor of Audiology student at UNC. Her clinical interests include working with children who have neurodevelopment disabilities, in addition to hearing loss. She is passionate about multi-disciplinary care and how the team approach to care can benefit patients and their families.

Amber Collins is a second year PMHNP student at UNC. She is a parent of an autistic child who fuels her passion for the autistic community and shedding light on the portion of the community that is diagnosed later in life. Ms. Collins intends to be of service to the autistic community as an advocate and in her career as a PMHNP.



Carol Conway is mom to an adult son with Kleefstra syndrome, which leaves him mostly nonverbal, with cognitive delays and behavioral challenges. She chairs a grassroots group of over 250 families called PACID: Parent Advocates for Adult Children with I/DD. She is also on the board of The Arc of NC and member of the NC Council on Developmental Disabilities.

Casey DeMarco is a pediatric physical therapy resident at UNC. She completed her undergraduate degree at UNC and her Doctor of Physical Therapy degree from Western Carolina University. Her professional interests include advancing the role of physical therapists as primary care providers, providing equitable access to health care, and serving underrepresented populations.

Julia Eden is a graduate student in social work. Her experience with direct support, advocacy, and systems navigation has inspired her to seek more in-depth training to serve people with intellectual and developmental disabilities.

Clare Feole is a self advocate who graduated from Carrboro High School and attended Alamance Community College's Career College program. She currently takes classes in Early Childhood at Alamance Community College and works part-time at a garden center and a child care center. She is an active Special Olympics athlete and lives independently with support from her family.

Hannah Gray is a third-year doctoral student studying audiology from Tulsa, OK. Her career aspirations are to work with children who are severe-profoundly deaf and require the use of cochlear implants to use spoken language.

NC-LEND 2023-2024 Trainees and Fellows *continued*

Sienna Halterman is an undergraduate majoring in Biology and Sociology with strong interests in disability studies. Sienna's research interests include understanding how development varies across neurodevelopment disabilities and the impact of sex and gender on the expression and diagnosis of ASD.

Caisi Hecht is a clinical research coordinator at the CIDD. Her research work is primarily focused on novel therapeutics for individuals with rare neurodevelopmental disorders. Caisi is passionate about furthering her clinical and research career working with individuals with IDDs/NDs and providing patients with empathic care.

Sarah Hubbard is a LEND self advocate. She graduated from Western Carolina University and enjoys meeting new people.

Nadin Abu Khalaf is a Speech Language Pathology graduate student at UNC. Her research interests include multicultural issues in autism, early identification and intervention of neurodevelopmental disorders, and bilingualism. Through LEND, she hopes to gain knowledge on neuro-developmental disorders to combat social stigma in ethnic minority communities.

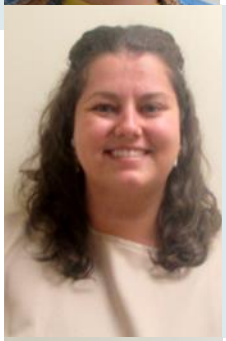
Emily Lagnese supports patients and their families as the Clinical Assistant at the CIDD. She is interested in advocating for and providing mental health services to family members of individuals with IDD and hopes to combine psychology and special education to better serve children with I/DD and their family members through childcare, education, and mental health resources

Ashley Layne is a student in the Master of Science in Occupational Therapy program at UNC. She is a research assistant for the UNC Diabetes Research and Wellness Lab and looks forward to working with the I/DD community in her clinical work at the CIDD, through the LEND program, and in her fieldwork sites in the coming year.

Hayden Loeb is a research assistant at UNC TEACCH investigating how young adults with IDD access community resources, including post-secondary education, multicultural materials, and opportunities for exercise. Previously, she was a direct support professional at TEACCH's Carolina Living & Learning Center, and a medical scribe for IDD clinics within UNC's Physical Medicine & Rehabilitation department.

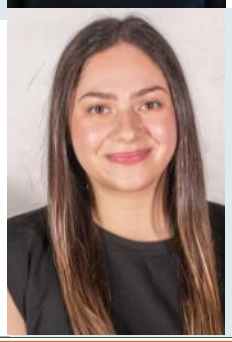
Selena Marcum is a a third-year Doctor of Audiology Student. Her clinical interests include working with children with hearing loss and other developmental disabilities and their families.

Amanda Maxson is a Master's student in Social Work. Her professional goals are to partner with disabled individuals to foster self-efficacy and leadership skills. She is also interested in supporting Latinx families in their journey accessing disability services.



Karys Normansell-Mossa is a predoctoral psychology intern at UNC and a neuro-divergent self-advocate. Her research and clinical interests are at the intersection of gender and autism, especially in working with gender nonconforming and transgender autistic folks. She is passionate about supporting the overall mental health and wellbeing of queer autistic people as well as other multiply marginalized groups.

Maria Novak is a doctoral student in UNC's School Psychology program and a graduate research assistant for the CIDD. She studies the impact of early adverse experience on the developing brain. Her hope is that by studying the functional and structural changes that accompany the onset of child psychopathology, we may arrive at targets for intervention, potentially preventing their emergence into adulthood.



Janette Ramirez is a Bilingual Speech Pathology graduate student at UNC. Her goal is to work with pediatric populations, specifically with communication and language, and serve as an ally for the disability community. She has experience working with Spanish-speaking families and students with intellectual disabilities focusing on empowering patients to find their voice and live a quality life.

NC-LEND 2023-2024 Trainees and Fellows *continued*

Kelly Real is the Recruitment Coordinator for the CIDD Research Registry. She graduated from UNC with a degree in psychology and plans to attend graduate school in social work. Her interests include advocating and improving accessibility to services for historically marginalized communities and breaking the language barrier between clinician and patient in the Latinx community.

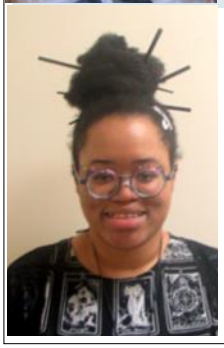
EV Vickery is a dual master's student in social work and public health. She has worked in education settings with students with disabilities and is passionate about providing inclusive and equitable education to all students.

Rebecca Scothorn is a MPH Nutrition and Dietetics student in the Gillings School of Global Public Health. Her research and clinical interest include early diagnosis and treatment of feeding disorders, along with increasing overall food access in part via WIC and SNAP. Through this program, Rebecca hopes to learn how various intersecting identities, including all neurodevelopmental disorders, can affect an individual's relationship with food and what the field of Public Health can do to help improve lifelong outcomes.

Kiera Walker is a doctoral student at UNC and an extern in the CIDD clinics. She was previously an elementary school teacher and learning specialist, which is where her interest in meeting the needs of all learners was ignited. Currently, her research interests are around school-based mental health supports for students, specifically individuals with co-occurring developmental and mood disorders.

Taylor Thames is a Master of Public Health student in the Applied Epidemiology concentration at UNC Gillings School of Public Health and self-advocate. She graduated from Clemson University with a BS in Microbiology and strong biomedical background. In addition to an interest in infectious disease impact on underserved communities, Taylor also aims to address health disparities in adolescents and adults with developmental disabilities from an epidemiological and social perspective.

Jamie Watt is a registered nurse who works in a psychiatric emergency department and outpatient primary care. She is in her second year of the Psychiatric Mental Health Doctorate of Nursing Practice program at UNC. She hopes to practice in an outpatient clinic, whether it is a psychiatric-specific clinic or in a behavioral health integration role in primary care, and she has a passion for helping vulnerable populations.



Briana Thompson is a self-advocate with I/DD who works with Easter Seals UCP. She has done collaborations with Duke and PCORI to help advocate for people of color with I/DD.

Olivia Zimmerman is a third-year student in the audiology program at UNC. Olivia's research and clinical interests include cochlear implant outcomes in children, especially in patients with complex needs as well as family-centered interventions and equitable access to health care.

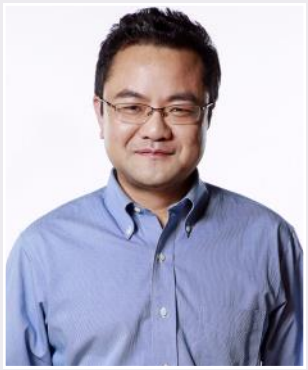
IDDRC Spotlight on Jessica Cohen, PhD

Jessica Cohen, PhD

Dr. Jessica R. Cohen is an Associate Professor in the Department of Psychology and Neuroscience. Her research uses neuroimaging to characterize functional brain network organization and dynamics across the lifespan, with the goal of understanding how cognition emerges from network functioning in both health and disease. Dr. Cohen takes a transdisciplinary approach to her research, incorporating cutting-edge methodology from neuroscience, psychology, and mathematics, such as resting state and task-based functional connectivity, graph theory, machine learning, and computational modeling.

Dr. Cohen is currently funded through the Biobehavioral Research Awards for Innovative New Scientists (BRAINS) program at NIMH. Her R01 examines how longitudinal changes in brain network organization across the transition to adolescence relate to improvements in executive functioning and risk-taking outcomes in youth with ADHD. She was previously funded through a K99/R00 award in which she conducted a methylphenidate challenge in children with ADHD. Through that research she identified features of brain network organization and dynamics that changed after methylphenidate administration and that led to improvements in executive functioning. Her research has benefitted from the IDDRC Clinical Translational Core, through which she recruits many of the participants in her research studies.

Study Published in Science Reveals Strong Connection Between Heart and Brain Health



Hongtu Zhu, PhD

Cardiovascular disorders correlate with some neurological and psychiatric conditions, but it is not always clear what the connections are and whether they are caused by an innate predisposition or by the stress induced by having a medical condition. A new study conducted by researchers from UNC-Chapel Hill, the University of Pennsylvania and Purdue University leverages large magnetic resonance imaging (MRI) data to shed light on the close relationship between cardiovascular diseases and brain diseases such as stroke, dementia and cognitive impairment, unraveling the underlying genetic signatures and inter-organ connections between the heart and brain.

Led by CIDD IDDRC Investigator, Hongtu Zhu, PhD, and the Biostatistics and Imaging Genomics Analysis Lab's Statistics and Signal group (BIG-S2) at UNC, the study was published in "Science," one of the top-ranked journals. The first author of the study is Bingxin Zhao, assistant professor of statistics and data science at the University of Pennsylvania and doctoral alumnus from the UNC Gillings School of Global Public Health. Additional authors include IDDRC Investigator, Jason L. Stein, and IDDRC Data Science Core Director, Yun Li.

In a genome-wide association study, the researchers successfully uncovered the genetic architecture underlying heart-brain connections. Furthermore, the study revealed shared genetic influences with cardiovascular and brain diseases. By deepening understanding of the intricate connections between the heart and brain, this study has significant implications for disease risk prediction and prevention. The multiorgan perspective in this study offers new opportunities to mitigate the negative impact of organ diseases on one another and improve overall human health.

Graham Diering Featured in Spectrum

Graham Diering, PhD, assistant professor of cell biology and physiology at UNC and an IDDRC investigator, was profiled in Spectrum earlier this year. Memories from Diering's life trace the rising star's scientific path from raising lizards as a child and later exploring home brewing to heading a lab that investigates memory, sleep disturbances and early development in animals with autism-linked mutations.

Read Asleep in the Mouse House with Graham Diering | Spectrum | Autism Research News

Study Shows Childhood Emotional Deprivation Alters Brain

After the fall of communism in Romania, thousands of children were discovered in institutional orphanages across the country. Because of high child-to-caregiver ratios, these children were neglected, with overall low levels of caregiving and very regimented non-individualized care.

Without a foster care program at that time in Romania, University of North Carolina researchers Charles Zeanah, Charles Nelson and Nathan Fox set up a new grant-funded foster care intervention program. This program was well supported, with frequent visits by a dedicated team of social workers to foster families.

Margaret Sheridan, PhD

Children were randomly selected to participate in this foster care program, providing scientists an unusual opportunity to study what happens to children's brains when they're deprived of attention and emotional connection.

"We know from years of animal work that experiences early in life shape brain development, but until now, this has never been shown conclusively in humans," says Margaret Sheridan, PhD, a clinical psychologist and IDDRC investigator at UNC, and the lead author on a new study showing that deprivation in early childhood shapes the development of brain structure through adolescence. Sheridan is also a former CIDD T32 mentor.

Sheridan and a team of researchers from the Bucharest Early Intervention Project published their findings in Science Advances. Their research shows that children who were randomly placed out of institutional care and into well-supported foster care before the age of 3 had changes in areas of the brain that support higher-order problem-solving years later when the children were 16.

In addition, children placed into high-quality foster care before 3 years old saw typical brain development from 9 to 16 years, in areas related to emotional reactivity, language and executive function, but this pattern was altered in children who were deprived of family care.

"Here we show that that the opportunities that a child has in early life to learn and grow will impact not just their behavior but their actual brain development and brain structure for years to come," says Sheridan. "Children need invested caregivers supporting their development from a very early age."

The Bucharest Early Intervention Project, launched in 2001, is a landmark study of the impact of institutionalization, a severe form of neglect on child development. It is the only randomized controlled trial of foster care as an alternative to institutional rearing. Between the ages of 6 and 33 months, 68 children were removed from orphanages and placed in high-quality foster care. Families who received a foster child were frequently visited by a social worker and given significant financial support, which helped families integrate and provide support. The children have been tracked throughout their childhoods, and initial evidence of the negative impact of institutionalization on development changed the way Romania approached childcare and family leave.

"This new evidence shows what doesn't happen to children matters just as much as what does happen for child brain development," says Sheridan.

Q&A with Margaret Sheridan

Why did you decide to do this analysis?

Adversity has been linked with changes in the brain and body in many correlational studies. This has led researchers to hypothesize that early adversity "embeds" in the body, changing how the brain and body develop. In particular, researchers suspect that early adversity has this impact because childhood is characterized by enhanced plasticity — as the brain develops it grows to be the most efficient for the environment it will encounter in the future, so early environments appear to preferentially shape brain development. The impacts of early environments on brain development have been demonstrated experimentally in rodents. However, until now we lacked experimental evidence that this same process happened in humans.

We wanted to demonstrate that early adversity doesn't just change how you think or feel later but that changes in your environment which start even before you can remember shape the development of your brain years later. The early brain plasticity that I mention above is implemented through changes to cortical structure. This is why we were interested in neural structure.

Q&A continued on next page.

Q&A with Margaret Sheridan *continued*

Why use MRI scans at age 9 and then age 16, specifically?

As children enter adolescence, we see a rapid increase in social development with adolescents establishing new long-term social networks and supports as well as a rapid uptick in mental health problems. These social changes are accompanied by changes in neural structure and function. We studied neural structure very early and later in adolescence, capturing how the brain was shaped by early development during this second period of developmental plasticity.

You found that children in institutional care had significantly decreased thinning compared with those randomly placed in foster care. What does this quantitatively mean? Was there a percentage difference by which this decrease was observed?

It's very difficult to quantify the size of this effect due to the methodological approach, but I think the association between brain differences and behavioral outcomes we care about, such as IQ and mental health, really speak to the importance of these results.

Why are your results important both for the scientific community and for public health?

These findings clearly demonstrate the causal impact of positive caregiving environments on brain development in humans. The brain is our organ of behavior, emotions and cognition. If we want healthy adolescents, they need healthy brains. In recent times conversation has focused on how to better support caregivers through early pre-K programs, better family social services and health care. If these kinds of supports provide resources to families so that they can focus on parenting, those programs will support healthy brain development.

Eva Anton Receives NIH High Risk-High Reward Grant

Eva Anton, PhD

On the surface neurons are cilia – tiny microtubule appendages that serve as antenna for cells to sense and respond to signals from other cells. Their role is not the same as cells communicating through the typical network of axons and dendrites, but scientists now think that disrupted primary cilia signaling plays a role in neuronal circuit formation and function. When cilia signaling is disrupted, the result can be brain malformations and neurodevelopmental disorders, including autism, schizophrenia, and epilepsy.

Eva Anton, PhD, professor in the UNC Department of Cell Biology and Physiology, a primary faculty member at the UNC Neuroscience Center, and an IDDRC Investigator, studies neurodevelopment and has been awarded an NIH Transformative Research Award, together with Jeff Lichtman, MD, PhD, the Santiago Ramón y Cajal Professor of Arts and Sciences at Harvard University, and Ryohei Yasuda, PhD, director of the Max Planck Florida Institute for Neuroscience, to elucidate cilia-driven signaling with the end goal of mending neuronal circuitry and treating disorders.

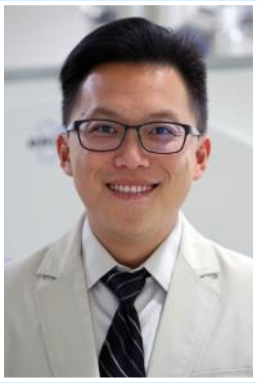
The NIH Common Fund supports a series of exceptionally high-impact programs that cross NIH Institutes and Centers. Common Fund programs pursue major opportunities and gaps in biomedical research that require trans-NIH collaboration to succeed. The High-Risk, High-Reward Research program, part of the NIH Common Fund, manages four awards – the Pioneer Award, the New Innovator Award, the Transformative Research Award, and the Early Independence Award.

Each one is considered part of the NIH Director's Awards Program, given to exceptionally creative scientists proposing high-risk, high-impact research at all career stages. These prestigious awards were created to support unconventional approaches to major challenges in biomedical and behavioral research. This year, announced this week, the NIH awarded more than $200 million to support potentially transformative biomedical research projects.

Anton's project aims to precisely and comprehensively delineate primary cilia-driven signaling mechanisms animating neuronal function and malfunction in the cerebral cortex. Understanding the molecular logic of primary cilia's role in neuronal functional dynamics and the relevance of this paradigm for neural circuit malfunction in humans will enable researchers to use primary cilia signaling as a tool to mend neural circuit disorders.

T32 Post-Doctoral Research Training Program students attended the T32 Postdoc Seminar Series on November 15, 2023 - "Structural and Functional Neuroanatomy" presented by Dr. Laura Ornelas. Pictured during the sheep brain dissection session are some of the students present. Left to right: Tyler Mcfayden, Jiseok Lee, Ian Curtin, Jieun (Esther) Park.

IDDRC Investigator Ian Shih Receives a $2.4 million NIH Grant to Improve Functional Brain Imaging Techniques

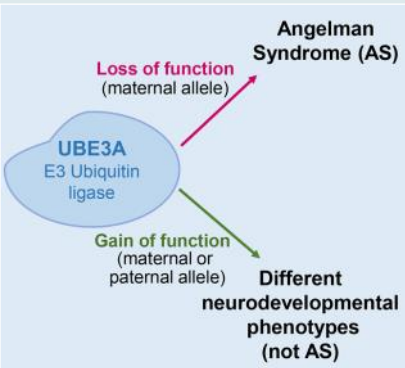


Ian Shih, PhD

Professor and Vice Chair for Research at the UNC Department of Neurology, Ian Shih, PhD, has been awarded a $2.4 million grant from the National Institutes of Health (NIH) to transform functional magnetic resonance imaging (fMRI) methods. Shih's project aims to improve brain activity mapping using innovative imaging sampling scheme. For nearly three decades, echo planar imaging (EPI) has been the standard fMRI technique for rapid whole brain scans, measuring blood oxygenation – a key brain activity indicator. However, it faces challenges like acoustic noise, motion artifacts and limited sensitivity and specificity compared to other methods. The Shih lab aims to develop a 3D brain-wide imaging method called Steady-state On-the-Ramp Detection of INduction-decay signal with Oversampling (SORDINO). This sequence holds potential to address current fMRI issues while improving sensitivity and specificity. The project's objectives are to advance, validate and introduce SORDINO to fMRI in experimental animals. The team will optimize imaging parameters, explore contrast mechanisms and study SORDINO's performance. The outcomes of this project could enhance fMRI technologies, leading to improved brain imaging methods and potential human applications in the future.

Autism-linked UBE3A gain-of-function mutation causes interneuron and behavioral phenotypes when inherited maternally or paternally in mice

Angelman Syndrome (AS) is a severe neurodevelopmental disorder caused by deletion or mutation of the maternal allele of UBE3A, a gene whose mutation has also recently been associated with autism spectrum disorders.



In this study published in Cell Reports, using CRISPR/Cas9 technology, IDDRC investigator and UNC Neuroscience Center Director, Dr. Mark Zylka and his team introduced a UBE3A T503A mutation to the wildtype Ube3a gene to model the human UBE3A T485A mutation. This mouse model allows the researchers to precisely control the parent of origin of the UBE3A T503A mutation to investigate whether its parent of origin effects impact brain development. For this purpose, the researchers thoroughly characterized three types of mutant mice, including mice carrying mutations inherited maternally, paternally and from both parents. The researchers found that elevated UBE3A activity when the mutant form is expressed in mice carrying a maternally inherited UBE3A T503A mutation, in all cell types in the brain. In mice carrying a paternally inherited mutation, a broad gain of UBE3A function was only transiently observed at an early embryonic stage and in adult brain UBE3A was restricted to non-neuronal cells.

Future research will focus on understanding the mechanisms by which UBE3A gain of function mutations affect brain development and inform approaches to neutralize elevated UBE3A activity as a potential treatment for these disorders.

UNC Brain Development Study of Infants with Angelman Syndrome and Fragile X Syndrome

Do you (or someone you know) have a baby with Angelman syndrome (AS) or fragile X syndrome (FXS)?

You can help us identify the earliest brain and behavioral features of AS and FXS by participating in the first MRI research study of its kind.

Who is eligible?

Infants between birth and 24 months of age with AS or FXS.

What Does Participation Involve?

- Traveling to the University of North Carolina at Chapel Hill (UNC) for two in person visits between **6 and 24 months of age**.
- Behavioral and cognitive assessments at each visit (at no cost to the family) - with a summary of results for the family.
- A safe, non-invasive MRI brain scan during natural sleep (no anesthesia or sedation involved) - with a copy of the MRI for the family.

Goal of this Research

Studying the early brain and behavioral development of infants with AS and FXS could aid in the future development of better supports and treatments.

Compensation

- All travel costs to Chapel Hill, North Carolina (airfare, hotel, rental car, meals) will be covered by the study.
- In addition, your family will be compensated up to $200 for participation in this study.

To enroll or ask questions, contact study coordinator: Zumin Chen

Phone: + 1 919-966-8032 I Email: shenlab@unc.edu

This study is led by Principal Investigator: Mark Shen, PhD, Assistant Professor of Psychiatry & Neuroscience
UNC School of Medicine

Support the Carolina Institute for Developmental Disabilities

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 UNC Health Foundation gifting page and choose "Carolina Institute for Developmental Disabilities:" Click Here.

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