



Inside the Institute

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Commitment to Diversity, Equity, and Inclusion and Statement of Solidarity

The events of 2020, including the COVID-19 pandemic and acts of violence against Black people and other people of color across the nation, have exposed underlying structural inequalities and highlighted the enduring crisis of racism. The CIDD recognizes that more must be done to combat these systemic inequities and empower action toward eliminating racism, discrimination, and all forms of intolerance.

Following the racial tensions that ensued after the murder of George Floyd last spring, the CIDD formed a working group to construct a statement that reflects the Institute's position on Diversity, Equity, and Inclusion (DEI) and a statement of solidarity and commitment to anti-racism and anti-discrimination. The group put in countless hours of discussion and drafts were circulated for confidential feedback among the CIDD faculty and staff.

Diana M. Cejas, MD, MPH, Assistant Professor of Neurology at the CIDD, initially introduced the importance of addressing DEI and was a leading voice in the working group. "This summer, I voiced my thoughts and concerns about how CIDD could stand up against discrimination and how taking a strong stance and committing to addressing our own DEI issues could help us provide better care and make our center feel more welcoming to people of all backgrounds," said Dr. Cejas. "It was incredibly encouraging to hear that many other people on the faculty felt the same."

With consultation from Nate Thomas, PhD, the Vice Dean for Diversity, Equity, and Inclusion in the UNC School of Medicine, the CIDD group started work on the DEI and solidarity statements, developing two statements to represent organizational views: (1) A Diversity, Equity, and Inclusion statement of values and commitments to addressing DEI as it impacts staff, faculty, trainees, and families served at the CIDD, and (2) A Solidarity Statement in direct response to recent and ongoing injustices and in support of Black and Brown communities.

"Once those statements were finished, we started to make plans to identify and address issues at CIDD," said Dr. Cejas. "I'm so proud of the work that we're doing and I sincerely believe that it will help us grow."

These important statements can be viewed in English and in Spanish on page 2 and 3 of this newsletter and on the CIDD website at this link: <http://cidd.unc.edu/about/Diversity/>

"We are committed to and engaged in doing the work necessary to improve diversity, equity, and inclusion and we stand against racism and racial injustice," said CIDD Director, Dr. Joe Piven. "We start with these statements as they bring us together in conversation and they communicate our intent more broadly to our peers, patients and families, and community. It is our hope that this serves as a starting point, both in our larger community and within our own organization, to begin to address the issues raised in both of these statements, with the hope of having a significant and tangible impact on the lives of individuals impacted by these disparities and injustices."

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CIDD Statement on Diversity, Equity, and Inclusion

The Carolina Institute for Developmental Disabilities (CIDD) serves individuals with neurodevelopmental conditions and their families by providing high quality, evidence-based clinical care, conducting cutting-edge research, and training health service professionals. At the CIDD, we recognize that neurodiverse individuals have myriad racial, ethnic, gender, religious, and other identities; this diversity is one of our community's many strengths, and we seek to understand and highlight it. Alongside the UNC School of Medicine, we are committed to creating a welcoming, inclusive, non-discriminatory, and anti-racist environment for all individuals and families we serve, as well as for our trainees, faculty, staff, and community partners. At CIDD, we commit to the following:

- Condemning discrimination, hatred, prejudice, and microaggressions, while promoting respect, compassion, and inclusivity.
- Working to uncover our own biases, to hold ourselves accountable, and to make positive changes.
- Providing high quality, culturally sensitive clinical services.
- Conducting research that represents the needs and experience of diverse populations and promotes health equity.
- Promoting cultural and linguistic responsiveness among our faculty, staff, and trainees.
- Listening and learning on an ongoing basis.

The CIDD considers the individuals and families we serve, our trainees, faculty, staff, and community partners to be members of our inclusive CIDD family. We value your perspectives and input and welcome feedback regarding our practices.

CIDD Statement of Solidarity

At the CIDD, we recognize neurodiverse individuals have numerous racial, ethnic, gender, religious, and other identities; this diversity is a strength of our community that we celebrate. We stand with individuals of all backgrounds and oppose discrimination and injustice in all forms.

Police brutality and other acts of racist violence disproportionately kill Black and Brown people. In addition, individuals with disabilities and mental health challenges are more likely to have negative encounters with law enforcement that lead to traumatic consequences. The COVID-19 pandemic has revealed staggering disparities affecting Black and Brown communities, individuals with disabilities, and, in general, the most vulnerable among us. Racist rhetoric and harmful stereotypes related to COVID-19 have resulted in increased harassment and targeted violence against Asian-Americans. These recent events highlight the longstanding problem of racism in our country and compel us all to fight against these structural and systemic issues.

The CIDD stands in solidarity with Black and Brown communities. We condemn racism, anti-Semitism, ableism, homophobia, transphobia, sexism, classism, xenophobia, and all other forms of discrimination.

We are committed to creating a welcoming, inclusive, non-discriminatory, and anti-racist environment for all individuals and families we serve, as well as for our trainees, faculty, staff, and community partners. We recognize the American healthcare system, of which CIDD is part, is plagued by individual and systemic biases, and these should be identified, evaluated, and prevented on an ongoing basis. As a first step towards addressing our own biases, the CIDD has established a Diversity, Equity, and Inclusion Committee that will be evaluating our current practices and developing an action plan consistent with the mission of the UNC School of Medicine.

The CIDD DEI Committee inaugural members include Diana Cejas (co-Chair), Morgan Parlier (co-Chair), Jessica Kinard, Margaret DeRamus, Stephanie Fox, Kathy Ellis, and Anna Ward.

A special thank you to the initial DEI and Solidarity work group members: Diana Cejas, Margaret DeRamus, Stephanie Fox, Jessica Girault, Laura Hiruma, Jessica Kinard, Jean Mankowski, Djenne-amal Morris, Morgan Parlier, Joe Piven, Becky Pretzel, Mark Shen, and Brian Wrihten.

Nuestro compromiso con diversidad, equidad e inclusión y declaración de solidaridad

En respuesta a la brutalidad policial contra las personas negras a nivel nacional, junto con las condiciones actuales de la pandemia Covid-19 que desvelan las injusticias económicas, educativas, y de atención médica que existen en nuestros sistemas de servicio, CIDD ha desarrollado un comité de diversidad, equidad e inclusión (DEI). Nuestro instituto reconoce que las injusticias dentro de varios sistemas existieron mucho antes y continuarán surgiendo y por eso estamos comprometidos a abordar estos temas continuamente. Con la consulta de Nate Thomas, PhD, Vicedecano de Diversidad, Equidad e Inclusión en la Facultad de Medicina de la UNC (SOM, por sus siglas en inglés), hemos desarrollado dos declaraciones para representar nuestros valores como una organización: (1) Una declaración de diversidad, equidad e inclusión con nuestros valores y compromisos para abordar la DEI, ya que impacta a nuestro empleados, profesores, estudiantes y las familias atendidas por el CIDD; y (2) Una Declaración de Solidaridad en respuesta directa a las injusticias recientes contra las comunidades negras y morenas.

Declaración de CIDD sobre diversidad, equidad e inclusión

El Carolina Instituto de Discapacidades del Desarrollo (CIDD, por sus siglas en inglés) atiende a personas neurodiversas y a sus familias brindándoles atención clínica de alta calidad basada en evidencia científica, realizando investigaciones de vanguardia y capacitando a profesionales de servicios de salud. En el CIDD, reconocemos que las personas neurodiversas también tienen una gran variedad de identidades raciales, de género, religión y otras identidades más; esta diversidad fortalece nuestra comunidad, y buscamos comprenderla y resaltarla. Juntos con la Facultad de Medicina de la UNC, nos comprometemos a crear un entorno acogedor, inclusivo, no discriminatorio y antirracista para todas las personas y familias que nos visitan, nuestros estudiantes, profesores, personal y socios comunitarios. En CIDD, nos comprometemos con lo siguiente:

- Condenar la discriminación, el odio, los prejuicios y las micro-agresiones y promover el respeto, la compasión y la inclusión.
- Esfuerzo colectivo para descubrir nuestros propios prejuicios, hacernos responsables y hacer cambios positivos.
- Proporcionar servicios clínicos de alta calidad que son culturalmente sensibles.
- Realizar investigaciones que representen las necesidades y experiencias de identidades diversas y promuevan la equidad en salud.
- Promover la receptividad cultural y lingüística entre nuestra facultad, personal y estudiantes.
- Continuar escuchando y aprendiendo de las comunidades que atendemos.

El CIDD considera que todas las personas y familias que atendemos, nuestros estudiantes, profesores, personal y socios comunitarios son miembros de nuestra familia inclusiva de CIDD. Valoramos sus perspectivas y agradecemos sus comentarios sobre nuestras prácticas.

Declaración de solidaridad de CIDD

En el CIDD, reconocemos que las personas neurodiversas también tienen una gran variedad de identidades raciales, de género, religiosas y otras identidades más. Esta diversidad fortalece nuestra comunidad y merece que la celebremos, por eso apoyamos a todas las identidades y nos oponemos contra la discriminación y la injusticia.

La brutalidad policial y otras formas de violencia racista matan de manera desproporcionada a personas negras y morenas. Además, las personas con discapacidades y problemas de salud mental tienen más probabilidades de tener encuentros traumáticos con la policía. La pandemia de COVID-19 ha revelado las injusticias que afectan a las comunidades negras y morenas, a las personas con discapacidades y, en general, a los más vulnerables entre nosotros. La retórica racista y los estereotipos relacionados con COVID-19 han provocado un aumento de acoso y violencia dirigida contra la comunidad asiática. Estos acontecimientos recientes demuestran el problema antiguo del racismo en nuestro país y nos obliga a luchar contra estas injusticias estructurales y sistémicas.

El CIDD se solidariza con las comunidades negras y morenas. Condenamos el racismo, el antisemitismo, el capacitismo, la homofobia, la transfobia, el sexismo, el clasismo, la xenofobia y todas las otras formas de discriminación.

Estamos comprometidos a crear un entorno acogedor, inclusivo, no discriminatorio y antirracista para todas las personas y familias que atendemos, nuestros estudiantes, profesores, personal y socios comunitarios. Reconocemos que el sistema de salud estadounidense, del cual CIDD forma parte, está plagado de sesgos individuales y sistémicos, y deben ser identificados, evaluados y prevenidos de manera constante. Como primer paso para abordar nuestros propios prejuicios, el CIDD ha establecido un Comité de Diversidad, Equidad e Inclusión que evaluará nuestras prácticas actuales y desarrollará un plan de acción consistente con la misión de la Facultad de Medicina de la UNC.

Scientists Take Major Step Toward Angelman Syndrome Gene Therapy



Mark Zylka, PhD

Published in *Nature*, research led by Mark Zylka, PhD, at the UNC School of Medicine, shows how gene editing with CRISPR-Cas9 can restore function in an animal model of the neurodevelopmental condition Angelman syndrome. The research was recently highlighted in *Spectrum's* year-in-review as a notable paper for 2020 (listed #2!) and was also featured in *Spectrum's* "Hot topics in autism research: 2020."

Babies born with a faulty maternal copy of the UBE3A gene will develop Angelman syndrome, a severe neurodevelopmental disorder with no cure and limited treatments. Now, for the first time, scientists at the UNC School of Medicine show that gene editing and gene therapy techniques can be used to restore UBE3A in human neuron cultures and treat deficits in an animal model of Angelman syndrome.

This work, [published in *Nature*](#) and led by senior author Mark Zylka, PhD, Director of the UNC Neuroscience Center and W.R. Kenan, Jr. Distinguished Professor of Cell Biology and Physiology, lays important groundwork for a long-lasting treatment or cure for this debilitating disease, as well as a therapeutic path forward for other single-gene disorders.



Justin Wolter, PhD

"Our study shows how multiple symptoms associated with Angelman syndrome could be treated with a CRISPR-Cas9 gene therapy," Zylka said. "And we are now pursuing this with help of clinicians at UNC-Chapel Hill."

Angelman syndrome is caused by a deletion or mutation of the maternal copy of the gene that encodes the ubiquitin protein ligase E3A (UBE3A). The paternal copy of UBE3A is typically silenced in neurons, so the loss of maternal UBE3A results in a complete absence of the UBE3A enzyme in most areas of the brain. That's crucial because the enzyme targets proteins for degradation, a process that maintains normal function of brain cells. When that process goes awry, the result is Angelman syndrome, a brain disorder with symptoms that include severe intellectual and developmental disabilities, seizures, and problems with speech, balance, movement, and sleep.

"Turning on the paternal copy of UBE3A is an attractive therapeutic strategy because it could reverse the underlying molecular deficiency of the disease," Zylka said. However, the paternal gene is silenced by a long strand of RNA, produced in the antisense orientation to UBE3A, which blocks production of the enzyme from the paternal copy of the gene.

Members of the Zylka lab, including postdoctoral fellows Justin Wolter, PhD, and Giulia Fragola, PhD, set out to devise a way to use CRISPR-Cas9 to restore the UBE3A enzyme to normal levels by disrupting the antisense RNA. Preliminary data in cell cultures were promising, and Zylka received grants from the National Institutes of Health, the Angelman Syndrome Foundation, and the Simons Foundation to test their findings in human neurons and in a mouse model of the disease.

In the *Nature* paper, co-first authors Wolter and Hanqian Mao, PhD, both of whom were fellows in the NICHD-funded T32 Post-Doctoral Research Training Program at the CIDD, and UNC colleagues describe using an adeno-associated virus (AAV) gene therapy to deliver the Cas9 protein throughout the brain of embryonic mice that model Angelman syndrome. Because UBE3A is essential for normal brain development, early treatment is crucial.

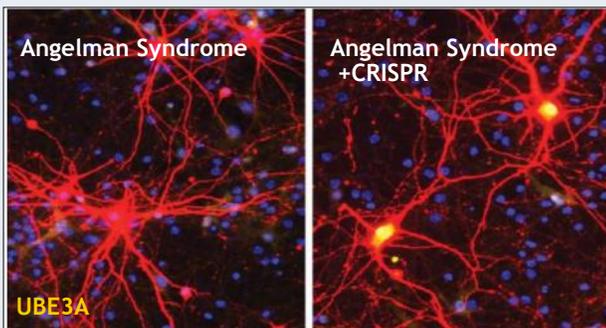


Hanqian Mao, PhD

The researchers found that embryonic and early postnatal treatment rescued physical and behavioral phenotypes that model core deficits found in Angelman syndrome patients. Remarkably, a single neonatal injection of AAV unsilenced paternal *Ube3a* for at least 17 months, and the data suggest this effect is likely to be permanent. The researchers also demonstrated that this approach was effective in human neurons in culture.

"We were blown away when we got these results," Zylka said. "No other treatments currently being pursued for Angelman syndrome last this long, nor do they treat as many symptoms. I am confident others will eventually recognize the advantages of detecting the mutation that causes Angelman syndrome prenatally and treating shortly thereafter."

Continued on next page



Left: UBE3A gene is off. Right: Using CRISPR, the gene is expressed and neurons fire (yellow).

Scientists Take Major Step Toward Angelman Syndrome Gene Therapy *continued*

Wolter added, "The results of treating early were very promising. Since we learned we could reduce the severity of Angelman syndrome in mice, we are now focused on refining our approach in ways that will be suitable for use in humans."

While working to translate this research into the clinic, the Zylka lab will collaborate with researchers at the Carolina Institute for Developmental Disabilities (CIDD) to identify symptoms in babies who have the genetic mutation that causes Angelman syndrome.

Zylka's lab is working with CIDD researchers led by CIDD director Joseph Piven, MD, to use brain imaging and behavior observations to identify symptoms associated with Angelman syndrome in infants. Anecdotal reports suggest these infants have difficulty feeding and reduced muscle tone, but these and other early symptoms have not been rigorously characterized to date.

"The idea is to use genetic tests to identify babies that are likely to develop Angelman syndrome, treat prenatally or around the time of birth, and then use these early symptoms as endpoints to evaluate efficacy in a clinical trial," Zylka said. "Our data and that of other groups clearly indicate that prenatal treatment has the potential to prevent Angelman syndrome from fully developing."

As part of the *Nature* study, the researchers also found that the gene therapy vector blocked the antisense RNA by integrating into the genome at sites cut by CRISPR-Cas9. This so-called "gene trap" could be exploited to disrupt other long non-coding RNAs and genes. Zylka added, "We are incredibly excited to keep this work moving forward with the hope of helping children and families overcome this debilitating condition. Support from the NIH, the Simons Foundation, and the Angelman Syndrome Foundation was essential for moving this work forward."

Along with Zylka, Wolter, and Mao, co-authors of the *Nature* paper are Giulia Fragola, PhD, postdoc in the Zylka lab at the time of this research; Jeremy Simon, PhD, research associate professor; James Krantz, Zylka lab research associate; Hannah Bazick, Zylka lab graduate student; Baris Oztemiz, Zylka lab research technician; and Jason Stein, PhD, assistant professor of genetics and member of the UNC Neuroscience Center; all at UNC-Chapel Hill.

This research was funded by grants from the National Institutes of Health, Simons Foundation, Angelman Syndrome Foundation, Eshelman Institute for Innovation, and Pfizer-NCBiotech Distinguished Postdoctoral Fellowship in Gene Therapy.

CIDD Think College Policy Advocates Team



Kenneth Kelty and Anna Ward on Zoom

Kenneth Kelty and Anna Ward were chosen to represent North Carolina as Think College Policy Advocates for 2021. The program is a partnership between the AUCD and Think College National Coordinating Center (NCC) which provides training, conference scholarships and 1:1 support for 10 teams consisting of one staff and one student or alumnus from inclusive postsecondary programs across the nation.

According to the NCC website, the purpose of the program is "to train students and professionals to be effective advocates for postsecondary education for students with intellectual disabilities." Teams attend

the 2021 Disability Policy Seminar (DPS) to be held virtually in Washington DC, April 19-22. The DPS is hosted annually by multiple nationally recognized disability rights and advocacy groups.

In addition to attending the DPS, team members will be expected to take part in Virtual Hill Visits and meet with Members of Congress and their state legislators, educating them on the impact and benefits of inclusive postsecondary education (IPSE). Both Mr. Kelty and Ms. Ward are excited about the possibilities this program can offer as they continue to advocate for NC to have more IPSE opportunities.

Kelty attended both Western Carolina's UP program and was a NC-LEND Trainee. He received the CIDD's Impact Award in 2019 and remains actively involved in advocacy work through the NC Empowerment Network, UCEDD and LEND, and as a motivational speaker. Ward served as Program Director for Appalachian's Scholars with Diverse Abilities Program and now is the Director of Advocacy and Inclusion at CIDD, working with UCEDD and LEND, the NC Postsecondary Alliance, and the HEELS 2 Transition programs.



Higher Education, Employment, Living Success
Supporting individuals with intellectual disabilities transitioning to adulthood

As 2020 came to a close and we begin a new year, the HEELS 2 Transition (H2T) programming has a lot to celebrate. Several years ago, the CIDD, under the vision of Deb Zuver and Donna Yerby of the CIDD, with the support of other UNC departments and community advocates, set out to develop a nationally recognized inclusive post-secondary education program (IPSE) for individuals with intellectual and developmental disabilities (I/DD), called HEELS UP. This program is modeled after Western Carolina University's (WCU) University Participant (UP) program and aligns with national standards for programs of its kind. IPSE's were created in response to the Higher Education Opportunity Act of 2008, which mandated that individuals with IDD be given opportunity to pursue higher education along with neurotypical peers. North Carolina has three existing IPSEs: WCU, University of North Carolina-Greensboro's Beyond Academics, and Appalachian State's Scholars with Diverse Abilities. The HEELS UP program and what subsequently evolved is now within the HEELS 2 Transition (H2T) umbrella and consists of 3 programs: HEELS Prep, HEELS UP and the newly developed HEELS Bridge.

In 2019, HEELS Prep (formerly Summer Intensive) was the first of the 3 programs to fully develop, as a collaboration between the TEACCH program, Allied Health, School of Education, and the CIDD, by first offering a week-long summer intensive and is now a 7-week summer program. HEELS Prep focuses on Life Skills Development for the transition to adulthood.



With the news in March 2020 that the university would suspend all face-to-face classes due to COVID 19, HEELS Prep was offered in an online format as HEELS Prep-Online. This program was 7 weeks long and enhanced with 1:1 student coaching supports. HEELS Prep-Online was an enormous success, in great part due to the competent and passionate graduate students who served as co-coordinators. HEELS Prep-Online support program was also offered for 7 more weeks in Fall 2020 as a way for students to continue practicing their skills.

The HEELS UP program delayed launching the pilot during summer 2020 in response to COVID -19 campus restrictions. After the success of the online version of HEELS Prep, H2T will be launching HEELS UP pilot, Summer 2021 as an online program.

Susan Lombardo and MJ Hayes of FullPower NC lead students in a HEELS Prep class on personal safety. Photo © 2020 Kidpower Teenpower Fullpower International

Having the benefit of gaining first-hand knowledge from the HEELS Prep-Online program about what prerequisite skills students with IDD would need for success in HEELS UP, as well as other IPSE programs, led to the design of HEELS Bridge. Students heading to an ISPE need a 'Bridge' with scaffolded skill development and supports to be successful in an ISPE program with online components. The HEELS Bridge program is an 8-week online curriculum that provides instruction needed to navigate the hidden curriculum in the higher education environment.

HEELS Bridge will be a requirement for the HEELS UP Cohort in summer 2021. Based on the success and knowledge gained from both the HEELS Prep-Online, and from the experiences of other IPSEs who had to move online, we will implement the originally planned HEELS UP launch in summer 2021 with supports from HEELS Bridge under the H2T umbrella. Furthermore, with continued support, we can proceed with our strategic planning for a full launch of HEELS UP for the 2022 Academic Year.

Former HEELS UP director, Deb Zuver, retired on May 1, 2020, and Anna Ward, the former Director and Principal Investigator of the Appalachian State University Scholars with Diverse Abilities Program, joined the CIDD and H2T leadership team in October 2020. As Director of Advocacy and Inclusion at the CIDD, IPSE program development is part of her position responsibilities at CIDD.

H2T fits directly within UNC's Mission to, "extend knowledge-based services and other resources of the University to the citizens of North Carolina and their institutions to enhance the quality of life for all people in the State." Because of the university and the CIDD's continued commitment to diversity and inclusion during these challenging times, we are able to continue work on the H2T programming and learn new avenues for providing evidence-based instruction and coaching to individuals with IDD.

Tuberous Sclerosis Complex Associated Neuropsychiatric Disorders (TAND) Clinic Opens at CIDD



Jamie Capal, MD

Jamie K. Capal, MD, Associate Professor of Pediatrics and Neurology, has recently started the second TAND clinic in the US, which is housed at the CIDD. TAND stands for Tuberous Sclerosis Complex Associated Neuropsychiatric Disorders. Approximately 90% of individuals with Tuberous Sclerosis Complex experience TAND-related symptoms at some point in their lives. TAND encompasses behavioral, intellectual, academic, psychiatric, neuropsychological, and psychosocial difficulties and represent a significant burden for patients and their caregivers. Dr. Capal is accepting children and adults with TSC for this clinic, both virtually and in-person if needed. If you would like to make a referral for an appointment, please [click here](#) to complete the CIDD Contact Form.

In addition, Dr. Capal is involved in the international TAND Consortium. Through this consortium, the TANDem Project (Empowering families through technology: a mobile health project to reduce the TAND identification and treatment gap) was launched. Goals of the TANDem project include: 1) Developing a self-report, quantified TAND Checklist and building the checklist into an app; 2) Developing consensus clinical guidelines for the identification and treatment of TAND; 3) Setting up a global TAND consortium that will include patients, family members, clinicians, and researchers.

The TAND Consortium has officially launched its website: <https://tandconsortium.org/>. The website features the TAND checklist and all of its translations. The Consortium has also launched a YouTube channel: <https://www.youtube.com/channel/UC9U4NJo6T81ui6wvvhPogQ> where people can find videos linked to the TANDem project and other TAND-related activities.



15q Clinical Research Network and the new Dup15q Syndrome Clinic

The CIDD is excited to partner with the 15q Clinical Research Network (CRN), a collaboration between the Angelman Syndrome Foundation (ASF) and Dup15q Alliance. The 15q CRN was established to create a consortium of leading medical and research institutions from around the world to provide expert medical care for individuals with Angelman syndrome and Dup15q syndrome (two rare conditions that occur due to a problem with the same region of the 15th chromosome). The CIDD established an interdisciplinary Angelman Syndrome Clinic nine years ago, and in September 2020, we conducted our inaugural Dup15q Syndrome Clinic through telehealth!

For more information about the 15q CRN, please visit: <https://15qclinicalresearchnetwork.org>.



Angelman Syndrome Foundation (ASF) Walk

Join the UNC/CIDD team for the Angelman Syndrome Foundation (ASF) Walk in Charlotte, NC on Saturday, May 15, 2021! There are options to join our team virtually or just donate to support our Angelman syndrome community.

Follow this link to our team page: <https://secure.e2rm.com/p2p/fundraising/349779/team/934604/en-CA>

CIDD and IDDRC Researchers Awarded 5-Year NIH Grant to Study Cerebrospinal Fluid Abnormalities in both Infants & Mouse Models



A multidisciplinary team of researchers, led by Principal Investigator Mark Shen (*pictured left*) and co-PI Ben Philpot, have been awarded a 5-year, \$1 million grant from the U.S. National Institutes of Health to conduct a new study of cerebrospinal fluid (CSF) abnormalities in neurodevelopmental disorders (P50 HD103573 Project 8084). The study is the “Signature Research Project” of the recently funded NICHD P50 Center Grant at CIDD: the UNC Intellectual and Developmental Disabilities Research Center (IDDRC).

The study will examine the function and physiology of CSF – the fluid that continuously cycles throughout the brain and then drains into the newly discovered lymphatic system of the brain – thereby cleaning the brain and flushing out neuroinflammation. [Dr. Shen’s team](#) previously published three independent studies showing that infants and toddlers who later developed autism had excessive CSF surrounding the brain by 6 months of age: before the onset of clinical symptoms, and 2 years prior to diagnosis. Preliminary research from Shen and Philpot labs indicate that this CSF abnormality is present in other neurodevelopmental disorders, and that the excessive CSF is potentially stagnant and therefore not clearing out neuroinflammation.

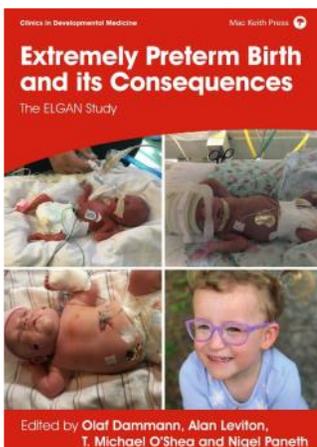
The new study will conduct non-invasive research with infants with neurodevelopmental disorders, and mechanistic studies in corresponding mouse models. The team will non-invasively measure CSF flow using longitudinal MRI scans from 6-24 months of age, in four groups of infants: Fragile X syndrome (FXS); Angelman Syndrome (AS); Infants at elevated likelihood for developing autism (due to having an older sibling with autism); Typically developing controls.

The team will also ‘reverse-translate’ findings in infants to mechanistic studies in genetic mouse models of these conditions to study: *in vivo* MRI scans of CSF flow, neuroinflammation, and the brain’s lymphatic system. This is the first study in neurodevelopmental disorders to examine CSF physiology and the recently discovered lymphatic/glymphatic systems of the brain.

Dr. Shen (Assistant Professor tenure-track at CIDD, Psychiatry, and Neuroscience Center) and Dr. Philpot (Professor of Cell Biology & Physiology and Associate Director of the Neuroscience Center) will lead a multidisciplinary team of Co-Investigators with expertise in both infant and animal research: infant neuroimaging (Martin Styner and Xiaopeng Zong); mouse neuroimaging (Ian Shih and SungHo Lee); infant clinical assessment (Heather Hazlett); one of the world’s experts in the lymphatic system (Kathleen Caron), and the co-discover of the glymphatic system in the brain (Jeff Iliff). In addition, the grant will support the efforts of several new research staff (including study coordinator Julia Gross) and postdoctoral fellows (including CIDD T32 postdoc Dea Garic).

Interested families with an infant (either with FXS, AS, or who has an older sibling with autism) can contact shenlab@unc.edu for more information.

Extremely Preterm Birth and its Consequences: The ELGAN Study



Distinguished Professor of Pediatrics and Division Chief of Neonatal-Perinatal Medicine at UNC-Chapel Hill and member of the UNC IDDRC. O’Shea, along with colleagues Alan Leviton, Nigel Paneth, and Olaf Dammann, edited the book “Extremely Preterm Birth and its Consequences” recently published by MacKeith Press. This book summarizes the results of the ELGAN (Extremely Low Gestational Age Newborn) study, the largest and most comprehensive multicenter study ever completed for this population of babies born before 28 weeks’ gestation.

O’Shea was a member of the team of researchers who wrote the initial ELGAN grant in 1999-2000 and led the study at Wake Forest from 2002-2015. Since 2015 he has led the ELGAN Study at UNC. His interest in extreme prematurity began 40 years ago when he was an intern in the neonatal intensive care unit (NICU) at UNC, carrying for infants born extremely preterm. Over the next 4 decades he cared for infants in the NICU and directed the NICU Developmental Follow Up Clinics at Wake Forest and UNC. These experiences fostered a drive to search for ways to improve the lives of babies born extremely preterm. He currently is the co-principal investigator for the third phase of the ELGAN Study, titled ELGAN-ECHO.

The book, “Extremely Preterm Birth and its Consequences,” is intended as a concise distillation of the main findings from over 150 published manuscripts arising from the ELGAN Study, including epidemiological studies of the antecedents and outcomes associated with early life inflammation and initiators of that inflammation. Chapter 1 of the book is available as a [free download](#).

Mark Zylka and Ben Philpot Receive 2020 CIDD Impact Award

The Carolina Institute for Developmental Disabilities (CIDD) Impact Award recognizes outstanding and lasting contributions of a professional, family member, or self-advocate within North Carolina's developmental disability community, toward improving the quality of life for individuals and their families. The 2020 CIDD Impact Award was given to two individuals whose contributions are inextricably inter-woven, Mark Zylka, PhD, and Ben Philpot, PhD.



Drs. Ben Philpot and Mark Zylka

CIDD Director, Joe Piven, presented the award to Drs. Philpot and Zylka during the CIDD holiday Zoom gathering in December.

Zylka and Philpot share leadership of the UNC Neuroscience Center, Dr. Zylka as Director and Dr. Philpot as Associate Director. Together they laid the groundwork for critical aspects to move forward our understanding of the biology of Angelman Syndrome (AS), put the CIDD on the map as one of the premiere clinical centers for AS care, and most importantly have an incredible impact on the lives of people with AS and their families.

Together they have published some of the most important papers about the biology of AS starting with Philpot's 2009 paper (*Nat Neurosci.* 2009 Jun;12(6):777-83. *Ube3a is required for experience-dependent maturation of the neocortex* Koji Yashiro ¹, Thorfinn T Riday, Kathryn H Condon, Adam C Roberts, Danilo R Bernardo, Rohit Prakash, Richard J Weinberg, Michael D

Ehlers, Benjamin D Philpot) on the aberrant development of synaptic plasticity, in *Nature NS*, to their groundbreaking work with Bryan Roth, which was the first ever to identify a drug that can effectively unsilence (or fix) an imprinted (or silenced) gene, *Ube3a*, in a mouse model of AS (*Nature.* 2011; Dec 21;481(7380):185-9. *Topoisomerase inhibitors unsilence the dormant allele of Ube3a in neurons* Hsien-Sung Huang ¹, John A Allen, Angela M Mabb, Ian F King, Jayalakshmi Miriyala, Bonnie Taylor-Blake, Noah Sciaky, J Walter Dutton Jr, Hyeong-Min Lee, Xin Chen, Jian Jin, Arlene S Bridges, Mark J Zylka, Bryan L Roth, Benjamin D Philpot).

Shortly after the *Nature* paper on topoisomerases unsilencing the AS gene, Philpot brought the annual meeting of the AS Foundation (ASF) to Chapel Hill where the ASF leadership toured the CIDD, leading to private funding to start an interdisciplinary clinic. With the help of many including Anne Wheeler, Margaret DeRamus, Mark Shen, and Heather Hazlett, we have established one of the leading clinics for AS in the country. These efforts have subsequently led to Mark Shen's and Jamie Capal's involvement in industry funded clinical trials.

Most recently, a truly groundbreaking paper in *Nature* earlier this year from Zylka's lab by lead author and former T32 post docs, Justin Wolter and Helen Mao, discussed a targeted therapy, using the technology of Crisper Cas9 to activate or fix the deficient paternal copy of the *UBE3A* gene in AS mice prenatally, and rescue the anatomical and behavioral phenotypes (or characteristics) of the disorder (see article on page 4) (*Nature.* 2020 Nov;587(7833):281-284. *Cas9 gene therapy for Angelman syndrome traps Ube3a-ATS long non-coding RNA* Justin M Wolter ^{1 2 3}, Hanqian Mao ^{1 2 3}, Giulia Fragola ¹, Jeremy M Simon ^{1 2 4}, James L Krantz ¹, Hannah O Bazick ¹, Baris Oztemiz ¹, Jason L Stein ^{1 4}, Mark J Zylka). This work has collectively changed the world of possibilities for people with AS and their families and put us on a path to effectively fix this devastating condition.

Zylka and Philpot have worked tirelessly to help our joint CIDD – Neuroscience Center efforts both as IDDRC investigators and leaders in our collaborative community of scientists. Philpot has been Piven's longtime partner in running the NIH funded post doc programs – where they have had a role in producing some of the leading basic researchers and clinician researchers on neurodevelopmental disorders in the country. And they have partnered in pushing forward key core resources shared between the two programs in our jointly supported Microscopy Core and the Bioinformatics component of our Data Science Core and major influences on our Mouse Behavior Phenotyping Core Lab.

Congratulations to both Ben Philpot and Mark Zylka, jointly the first researchers to receive the CIDD Impact Award!

Jessica Girault Featured in Autism Science Foundation 2020 Research Recap



A study led by Dr. Jessica Girault was highlighted in the Autism Science Foundation's annual review of autism science advances in 2020. Each year the Autism Science Foundation recaps the year's major scientific advances, and this year's issue highlights Dr. Girault's work towards the early detection and diagnosis of autism spectrum disorder (ASD) using a family study design.

The study, published in the *Journal of Neurodevelopmental Disorders* included a sample of 385 children with autism (probands) and their younger high-risk toddler siblings (n = 770 total participants) assessed as part of the multi-site Infant Brain Imaging Study (IBIS) led by Dr. Piven. Using parent-report of proband behavior on a common screening tool for autism, the Social Communication Questionnaire (SCQ), Girault and colleagues were able to predict the diagnostic outcome of high-risk younger siblings at 24 months. Each additional symptom endorsed for the proband on the SCQ increased the younger sibling's risk for ASD by 6%; this translates to nearly a 3-fold increase in risk between siblings of the lowest and highest scoring probands.

The study also included assessments of similarities in cognitive and behavioral abilities among proband-sibling pairs and found that communication abilities, and in particular receptive language, was strongly correlated among pairs where both siblings were diagnosed with ASD. Findings from this study suggest that ASD traits and behavioral profiles in probands have the potential to identify risk for ASD and specific areas of developmental concern in younger siblings at familial high-risk for ASD.

Dr. Girault presented this work at the NIH's annual meeting of the Autism Center's for Excellence in June of 2020 and results from this study served as preliminary data for her NIMH-funded K01 Career Development Award. This work launched a series of family-based studies using the IBIS sample that are currently underway to explore how familial traits may inform brain and behavior development in high-risk infants. Dr. Girault is also funded by the Foundation of Hope to extend this family study design to Fragile X and Down syndrome.



Diana Cejas Receives 2020 Broyhill Research Award in Child Neurology

Congratulations to Diana M. Cejas, MD, MPH, recipient of the UNC Broyhill Research Award in Child Neurology. The goal of the Broyhill Research Award in Child Neurology is to support novel studies of the developing nervous system or the impact of diseases on the developing nervous system. The awards are made annually with up to two years of support, and no more than two awards are made each year. Dr. Cejas was awarded \$12,500 to improve healthcare transition of patients with neurodevelopmental disabilities from a child-centered to an adult-oriented health care system. The study will identify factors that facilitate or hinder successful transition and then use the information to design a more effective healthcare transition program.



Brian WRIGHTEN Receives CIDD Initiative Award

Congratulations to Brian WRIGHTEN, recipient of the inaugural CIDD Initiative Award. The CIDD Initiative Award recognizes a staff member who goes above and beyond the normal expectations in service to the CIDD. CIDD Deputy Director, Jeff Low, presented the award to WRIGHTEN during the CIDD holiday Zoom call in December. "Brian consistently goes the extra mile, exceeding expectations in his many roles at the CIDD. He currently manages our clinical staff and facilities, while also serving as a member of our Information Technology Services team," said Low. "He has done an exceptional job juggling these responsibilities and always brings a positive attitude to any situation regardless of the challenge."

"Being the first recipient of the CIDD Initiative Award is very humbling and an honor. Receiving an award is never the reason for the work. But it always feels great to be recognized and acknowledged for what you do," said WRIGHTEN. "Although this award was given to me, no one ever gets anything done on their own. So I would like to thank my Clinical Staff for making me look good and all their hard work as well. Adjusting to working remotely in the midst of COVID was a challenge for everyone. I am just glad to do my part to ensure we continue to serve the families and the community that needs our help at the CIDD. I take pride in knowing that the work we do here will make a lasting impact on the lives of those we serve."

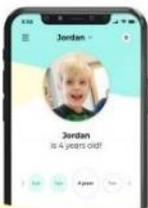
Act Early COVID -19 Response Grant

Faculty at CIDD were recently awarded 1 of 43 State and Territorial Act Early COVID-19 Response Teams grants through the Association of University Centers on Disabilities (AUCD) Act Early Network. The one-year grant is co-led by CIDD's Becky Pretzel, PhD, and Stephanie Fox, PhD, in collaboration with Sharon Loza, PhD, NC's Part C Coordinator and Early Intervention Branch Head. This nationwide initiative is focused on support for early childhood state systems through the Act Early Network to support recovery and strengthen resilience skills, behaviors, and resources of children, families, and communities. To this end, all grant recipients were asked to distribute a joint AUCD-CDC needs survey to key participants in their early intervention systems. Eight NC partners (i.e., Part C, Child Care Services Association, Title V, etc.) completed the needs assessment that identified barriers, opportunities and overall impact of COVID-19 on the early identification and intervention process. All data was analyzed by AUCD-CDC and NC's main findings were summarized by Claire Burns, PhD, CIDD postdoctoral psychology fellow.

Help your child grow and thrive

Your child's early years are so very important. Tracking how your little one plays, learns, speaks, acts, and moves helps you support their development.

Download CDC's free *Milestone Tracker* app to find fun and easy activities for each age.



In brief, results from the NC needs assessment suggested less family engagement with medical and child care providers for both in-person and virtual visits since the beginning of the pandemic. There also has been a decline in referrals for early intervention services, as well as in family participation in early intervention services delivered via telehealth.

Some recommendations for addressing reductions in engagement in early intervention services included increased provider training, family liaison/navigation support, referral coordination, increased engagement with local/community partners, and the provision of additional funding for resources (e.g., transportation, internet access, access to video technology).

The NC Act Early State team is working to target several of these barriers, including funding provider training, distributing educational materials and developmental monitoring resources such as "Learn the Signs. Act Early.", and supporting cross-systems collaboration.

B3 Coffee Creates Opportunities for Inclusion

B3 Coffee, founded by CIDD LEND Trainee, Jacklyn Googins, and fellow UNC student, Hannah Steen, is a non-profit pop-up coffee stand and online community that serves as a platform of positive visibility and community connection for people of all abilities. Through coffee and friendship, B3 Coffee enacts their core values of *Being, Belonging, and Becoming* better together (B3). One cup at a time, B3 Coffee aims to influence change toward a more inclusive and equitable world. Now more than ever, they are dedicated to bringing people together safely through virtual social and civic engagement opportunities. B3 Coffee offers consistent online programming including weekly team meetings and socials, monthly community leadership development seminars, barista trainings, and remote volunteer roles.

To learn more about B3 Coffee, contact Jacklyn Googins at jacklyn@b3coffestand.com or visit the B3 Coffee website <https://b3coffestand.com/>



UNC Has Enrolled over 3200 Individuals with Autism into SPARK



UNC has been a clinical site for the Simons Foundation [SPARK study](#) for over five years. SPARK is the largest genetic study of autism ever and aims to sequence the genetic information of 50,000 individuals with autism and their parents to discover the genes that cause autism. Currently, there are over 3200 individuals with autism associated with UNC who have enrolled in SPARK. Approximately half have sequenced genetic data and the other half have started the

participation process and received genetic sampling kits and are expected to have whole exome sequencing data available in the near future. Of these 3200, approximately 1400 are part of the UNC Intellectual and Developmental Disabilities Research Center (IDDRC) -supported [Autism Research Registry](#) (approximately 1000 have sequenced genetic data and the rest have started the participation process). UNC has achieved these impressive participation numbers through support from the Simons Foundation, the UNC IDDRC Autism Research Registry, the TEACCH program, and the UNC Neuroscience Center. Autism Research Registry families have indicated an interest in clinical research, and many have participated in past research studies at UNC. Principal Investigators associated with those studies typically retain the rich clinical data accrued from those studies.

We write now to alert the UNC IDDRC investigator community of this potential novel resource. Specifically, IDDRC investigators may recruit a sample of individuals with autism who have whole exome sequence data stored by the Simons Foundation. Since these families are local (often within a few hours driving radius) they could be enrolled in clinical studies. Those studies could involve cost-effective remote data collection. Alternatively, some data might be accessible through past UNC studies. In addition, SPARK also collects clinical data on these families. We believe there is a tremendous potential to take advantage of these resources by linking SPARK genomic data to local, potentially accessible families for studies involving clinical correlates of genomic information.

UNC investigators may access the genetic sequencing data from UNC-affiliated SPARK participants with autism through [SFARI Base](#), a clearinghouse for autism-related research data supported by the Simons Foundation Autism Research Initiative (SFARI). Interested investigators should contact Gabriel Dichter (dichter@med.unc.edu), a UNC SPARK co-PI and director of the UNC Autism Research Registry, for assistance with recruiting participants with SPARK genetic sequencing data for research studies.

Scan of Genomes for Inherited Variants Implicates New Gene Important in Autism

In a study published in [Translational Psychiatry](#), research led by Nana Matoba, PhD, co-supervised by Hyejung Won, PhD, and Jason Stein, PhD, assistant professors in the UNC Department of Genetics and members of the UNC IDDRC and Neuroscience Center, found that lowered expression of a gene called DDHD2 may increase a person's likelihood of autism.



Nana Matoba, PhD

IDDRC investigators Jason Stein and Hyejung Won teamed up with Joe Piven (CIDD director) and Yun Li (CIDD Data Core Center director) to investigate common variants associated with autism spectrum disorder (ASD) from the SPARK cohort (see article above). Post-doctoral research associate, Nana Matoba, co-supervised by Drs. Stein and Won, led the study.

While the majority of genetic studies of autism spectrum disorder (ASD) have focused on rare variants, the aggregated contribution of common variants to ASD has been previously found to be substantial. However, few individual common variants associated with ASD have been detected. Identification of specific variants associated with ASD may lead to a better understanding of what biological pathways cause the disorder. In this study, Dr. Matoba used genomic information of both parents and ASD children in the SPARK cohort and found the new genomic loci associated with ASD. One new locus identified in the SPARK dataset was also associated with multiple psychiatric disorders including schizophrenia, bipolar and obsessive-compulsive disorder. By integrating existing multi-level functional genomic resources, the team highlighted DDHD2 as a novel high confidence ASD-associated gene. DDHD2 is now registered as one of the SFARI genes (database for autism research community that is centered on genes implicated in autism susceptibility).

There are still many ASD genes or biological mechanisms that are yet to be clarified. To make further progress in ASD genetics, SPARK aims to recruit 50,000 families. If you are interested in or want to register, please access <https://sparkforautism.org/> or through the [Research Participant Registry Core](#).

CIDD Autism Imaging Research Published in National Geographic



National Geographic magazine featured research from the Carolina Institute for Developmental Disabilities, led by Joseph Piven, MD, CIDD director and the Thomas E. Castelloe Distinguished Professor of Psychiatry, Pediatrics and Psychology at the UNC School of Medicine.

Here's an excerpt:

"Scientists know that autism can be caused by a number of genes, both inherited and mutated, as well as other factors, such as the advanced age of a parent. One fraudulent study blamed it on the childhood vaccine for measles, mumps, and rubella – a provocative claim that has been disproved. Since the late 1990s, the disorder has become increasingly prevalent. Researchers

believe that's partly explained by improvements in diagnosis, but they haven't ruled out the possibility that the incidence is increasing, possibly due to biological and environmental factors.

Although researchers haven't established the precise origins of autism, they're gaining a clearer view of how it progresses.

Piven and his colleagues studied 106 infants who had an older sibling with autism, which meant they had a higher chance of developing the disorder. Scanning their brains at six months and again at 12 and 24 months using magnetic resonance imaging, the researchers found striking differences between the infants who later developed autism and those who didn't. The brains of infants who were subsequently diagnosed with the disorder grew faster than the others starting at six months, expanding more in surface area until 12 months, and then became larger in volume in the second year of life, the team reported in 2017."

The [complete article](#), which is behind a pay wall, includes the image featured here.

Gabriel Dichter Publishes UNC's First Simultaneous PET-MR Psychiatry Study of Autism



Professor Gabriel Dichter, CIDD investigator and Associate Director of the UNC Intellectual and Developmental Disabilities Research Center (IDDRC), and his colleagues published UNC's first simultaneous PET-MR psychiatry study in *Translational Psychiatry*. UNC was one of the first research institutions to have a scanner capable of combining positron emission tomography (PET) and magnetic resonance imaging (MRI). This technology allows for the simultaneous visualization of neuroreceptor populations from PET, high resolution brain morphology from structural MRI, and brain activation and connectivity from functional MRI.

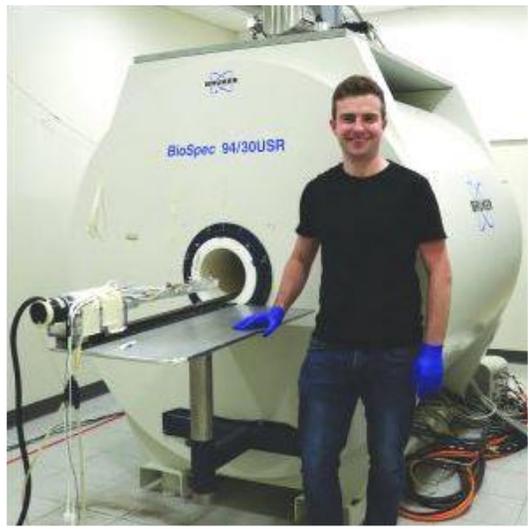
Dr. Dichter's lab used the tracer [¹¹C]raclopride to examine striatal phasic dopamine release to rewards and its relation to striatal activation and connectivity during reward processing in individuals with autism spectrum disorder. This finding, funded by the National Institute of Mental Health, adds to the growing body of research addressing social motivational impairments in autism.

Co-authors on this study included Erin Walsh, PhD, a UNC K awardee in Dr. Dichter's lab who is learning PET-MR methods, CIDD faculty member Jessica Kinard, PhD, graduate students Rachel Phillips and Paul Cernasov in UNC's clinical psychology program, BRIC faculty David Lalush, PhD, Eric Smith, PhD, and Zibo Li, PhD, and collaborators Jacob Hooker, PhD, and Nicole Zürcher, PhD from the Athinoula A. Martinos Center for Biomedical Imaging at Harvard University.

Simultaneous PET-MR neuroimaging has the potential to deliver unparalleled advances in our understanding of the brain basis of autism. It offers the promise of discovering molecular mechanisms underlying impaired neural functioning, attention, and behavior in autism. It also provides perhaps the most direct linkage possible between the brain basis of autism and preclinical autism models characterized by common molecular mechanisms. It additionally offers new ways to address autism heterogeneity by identifying subgroups of individuals with autism who share common molecular pathophysiology. Finally, it can help to discover new molecular brain targets to use to evaluate new autism treatments.

Dr. Dichter's lab is currently collecting a simultaneous PET-MR study addressing neuroinflammation in autism using a translocator protein tracer to visualize activated microglia.

Martin MacKinnon wins Bruker MRI Award



Congratulations to Martin MacKinnon, first place winner of the Bruker MRI Award for his entry iZTE-fMRI at the 2020 virtual meeting of the International Society for Magnetic Resonance in Medicine (ISMRM). MacKinnon is a Biomedical Engineering PhD student in the Preclinical Core/Center for Animal MRI, part of the UNC Intellectual and Developmental Disabilities Research Center (IDDR). MacKinnon demonstrated how a zero-echo-time (ZTE) technique can overcome several limitations of traditional fMRI experiments. Also, he showed that iZTE fMRI experiments can produce functional images with markedly less susceptibility artifacts and acoustic noise than standard GRE techniques. Martin said, "It was a great experience to win the Bruker MRI award and be able to speak to the preclinical imaging community alongside leaders in the field."

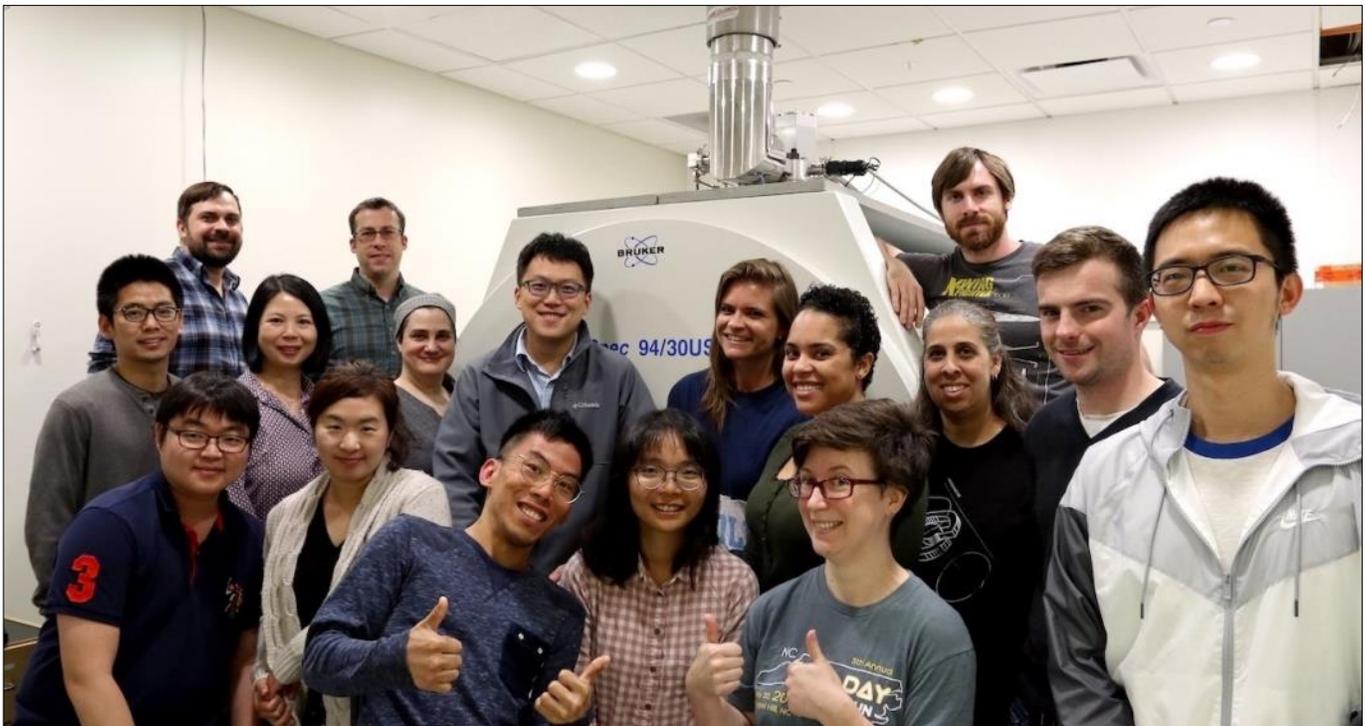
(Left: Martin MacKinnon stands beside Bruker Biospec 9.4T animal MRI scanner)

Center for Animal MRI Receives NIH Grants to Upgrade Facilities

Animal magnetic resonance imaging (MRI) research at UNC-Chapel Hill has been supported by a single Bruker Biospec 9.4T/30cm animal MRI system, which has been widely utilized by 96 investigators in the Research Triangle area of North Carolina, with the majority of the research projects focusing on the brain. Despite the center's efforts to upgrade the system hardware over the past few years, the scanner console of this Bruker system is now 14 years old and at the "end of life."

This year, the Center for Animal MRI (CAMRI) at the Biomedical Research Imaging Center (BRIC), led by Ian Shih, PhD, received two grants from the National Institutes of Health to upgrade the UNC School of Medicine's animal MRI research capabilities. The first \$2 million grant is to purchase a new 9.4T MRI scanner, and the second \$600,000 grant is to upgrade the current Bruker 9.4T MRI system. This new instrument and updated older machine will allow UNC School of Medicine researchers to conduct more advanced imaging research. Both 9.4T MRI systems will continue to be managed by an experienced team of researchers with technical expertise and a track record of operating this system for research.

"These NIH grants will improve our imaging capacity and extend the lifetime of extremely well-utilized imaging equipment at UNC, afford users the opportunity to pursue new cutting-edge methods of acquiring MRI data, and advance our journey towards understanding the anatomical and functional architectures in vivo using experimental animal models," said Shih, who is also an associate professor in the UNC Department of Neurology. Shih is pictured below with CAMRI team members.



NC Children with Complex Needs Training Series 2021

Implementation Supports in Best Practices & Case Consultation

The CIDD has partnered with Behavioral Health Springboard (UNC-CH School of Social Work) and the NC Division of Mental Health, Developmental Disabilities, and Substance Abuse Services to present a series of webinars to support workforce development for systems that interact with, support, and provide treatment for persons who have mental illness co-occurring with an intellectual/developmental disability. The training series will provide a combination of topic-specific didactic webinars alternating with interactive case consultation sessions covering the most common challenges in providing effective care to this population.

All sessions will take place via Zoom

Session Descriptions:

Support Transitions in Care in IDD

Will be held live on 3/23/2021 from 10 am – 11:30 am Speaker: **Diana Cejas, MD, MPH**

This session will review the key areas of transition from pediatric to adult care in the context of IDD. Medical and other areas of transition are inherently more complex and challenged by resource limitations for individuals with IDD. This talk will present a structure to help optimize transitions with emphasis on healthcare and utilizing a team approach.

Supporting Siblings of Individuals with Complex MH and IDD

Will be held live on 5/25/2021 from 10 am – 11:30 am Speaker: **Morgan Parlier, MSW, LCSW**

This presentation will discuss the various emotional challenges of the sibling of a family member of a child with complex needs. Additionally, the special role of this sibling in the family dynamic will be discussed, as well as various models of sibling support. Finally, resources and toolkits for assisting in the development of sibling specific mental health and support resources will be presented.

Case Consultations:

Will be held live from 10 am – 11:30 am on

4/27/2021 with **Dr. Rob Christian**

6/22/2021 with **Dr. Jean Mankowski**

The Case will be presented, participants will be asked to engage in a discussion of the case in terms of directed questions about other information that would be desired, and case facilitators/experts will also discuss what further information would be needed and why. Recommendations will be made regarding the case by both the participants and the experts. Discussion points will emphasize bio-psycho-social elements.

This training series targets behavioral health professionals, LME-MCO staff, medical professionals, nursing professionals, school staff, state and local child services agencies, and parents of youth who have dual diagnoses.

This training is free to attend but pre-registration is required.

TO REGISTER go to : <https://bhs.unc.edu/nc-cidd-training-series-20-21/dashboard>



2020 NC-LEND CIDD Trainee Research Award Recipients



Jessica Goldblum, currently pursuing the CIDD Certificate Program in Developmental Disabilities, is a third-year doctoral student in the UNC Developmental Psychology program under the joint mentorship of Dr. Cathi Propper and Dr. Clare Harrop. Ms. Goldblum has been awarded the 2020 CIDD Trainee Research Award, which will provide funds for her to attend the 2021 Gatlinburg Conference in Kansas City, Missouri. At Gatlinburg, Ms. Goldblum will chair a graduate student symposium entitled, "Masks, Mandates, and Mourning: Individuals with Neurodevelopmental and Genetic Disorders and Their Families During the Time of the COVID-19 Global Pandemic". Together with graduate student collaborators from Stonybrook University and UCLA, and discussant, Brian Boyd, this symposium will feature three presentations that examine the psychological, social, and economic impacts of COVID-19 on families and their children with disabilities. Ms. Goldblum's prospective symposium paper will showcase research on the compounded difficulties that children with autism spectrum disorder and their families face during COVID-19, including child anxiety, behavioral inflexibility, and difficulties with self-regulation; parent financial strain and distress; and heightened dysfunctional parent-child interactions. Collectively, this symposium will share findings from three unique, multidisciplinary research studies that seek to understand how best to support families and their children with neurodevelopmental and genetic disorders during current and future times of crises.



Delia Kan, BSc, a doctoral student in the Applied Developmental Sciences and Special Education program, has been awarded the CIDD Trainee Research Award. The award will provide funds for her to attend the Council for Exceptional Children 2021 Convention and Expo, originally at Baltimore, Maryland, but now virtual due to the COVID-19 pandemic. At the conference, Ms. Kan will be co-presenting findings regarding factors predictive of the type of high school diploma that are available to students on the Autism Spectrum. Her conference presentation used pre-intervention data from a large randomized control trial study conducted by The Center on Secondary Education for Students with Autism Spectrum Disorder (CSESA) on a comprehensive treatment program for adolescents with ASD in public schools. It is with hope that a better understanding of the characteristics which drive diploma tracking decisions will allow us to take a first step towards ensuring equity across diverse groups and improving postsecondary outcomes for all students on the Autism Spectrum. These analyses were conducted at the UNC School of Education in collaboration with Dr. Kara Hume and Lindsay Rentschler.



Madison Swisher, MS student in Clinical Rehabilitation and Mental Health Counseling at UNC School of Medicine, has been awarded the 2020 CIDD Trainee Research Award. Ms. Swisher is researching gender differences in types of focused interests and their effect on social camouflaging behaviors in Autism Spectrum Disorder (ASD). This award will provide funding to compensate future study participants. Understanding the interactions between gender, focused interest types, and camouflaging can refine ASD diagnosis to be more sensitive to gender differences and promote early conversations about camouflaging behaviors to encourage and support self-acceptance. Ms. Swisher is working in collaboration with her advisor Dr. Dara Chan, Dr. Clare Harrop, and LEND mentor, Dr. Jean Mankowski.

2021 CIDD "Virtual" Community Talk Series

All are welcome! Join us to learn about recent advances in developmental disabilities. FREE!

Meetings via ZOOM - Time: 6:30 – 8:00 pm FREE!

APRIL 14, 2021 "Changing Paths: Post-Secondary Options Pathways for Students with Disabilities"



Ann Palmer, BA (pictured left)

CIDD Family Faculty, Autism Society of NC Liaison, and author/coauthor of four books on the subject of autism

Baiyina Muhammad, PhD (pictured right)

Associate Professor of History at NCCU, former LEND Trainee at the CIDD

The speakers, both parents of young men with ASD, will describe their sons' college experiences - one in a program supporting students with I/DD, and one fully included with general campus supports. Discussion will include challenges students with autism or I/DD often face, how to access supports, the parent's role in supporting the student, and how parents can prepare the student for a successful transition to college.

MAY 12, 2021

"Dental Care for Children and Adults with Special Needs"



Sigurdur (Sigg) Saemundsson, DDS, MPH, MBA, PhD

Professor and Pediatric Dentistry Graduate Program Director Division of Pediatric Dentistry and Public Health UNC School of Dentistry

Dr. Saemundsson will talk broadly about dentistry for individuals with developmental disabilities, children and adults. He will address topics such as how to find a dentist for your child, what challenges face a child, parent, and dentist when a child with I/DD goes to the dentist, how to prepare for a visit, and many more topics.

For more information, contact: Debbie B. Reinhartsen, PhD, CCC-SLP

Debbie.Reinhartsen@cidd.unc.edu / 919-966-4138

Virtual Attendance Certificates—Professional Development 1.5 Credit Hours are available for each talk

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](#).

Email info@cidd.unc.edu or call 919-966-5171 for more information about supporting the CIDD.

Send us your comments or sign up to receive the newsletter: info@cidd.unc.edu

Newsletter Editor—Keath Low, MA