



Inside the Institute

The Carolina Institute Dedicates New Building

On October 22, 2010, our new building was officially opened with a festive ribbon cutting ceremony and reception. Opening remarks were made by Dr. William Roper, Chief Executive Officer of the University of North Carolina Health Care System, Dean of the UNC School of Medicine, and Vice Chancellor for Medical Affairs and by Dr. Joe Piven, Carolina Institute Director. Visitors, families, sup-



Joseph Piven M.D. (left) & Dean Roper M.D.

porters, and CIDD faculty and staff joined in on the celebration and tours of the new space were given.

The Carolina Institute is proud of its new building on a campus dedicated to providing cutting-edge services, research, and training to benefit individuals with developmental disabilities and their families. This new

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New Hearing and Development Clinic

The advent of newborn hearing screening in North Carolina ten years ago has dramatically decreased the age of identification and intervention for children born with permanent hearing loss. Unfortunately, more than one-third of those children will have additional challenges that range from severe, life threatening conditions at birth, to subtle learning problems that are not apparent until school age. Often there are



concerns about cognitive or social-emotional development. Many families report difficulty finding professionals who can address their concerns, and when they do it often requires multiple appointments with a variety of programs and professionals.

The new CIDD Hearing and Development Clinic (HDC) is responding to this need

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At the Carolina Institute for Developmental Disabilities, we support individuals with disabilities and their families by:

- Identifying and applying innovative solutions to complex issues using an interdisciplinary approach
- Studying best practices and translating research into practical applications
- Promoting self-advocacy, leadership, and inclusion by and for individuals with disabilities
- Training world-class leaders and experts in the field of developmental disabilities

TraCS Grant Awarded to Study Turner Syndrome



CIDD investigators Dr. Marsha Davenport (pictured to the left) and Dr. Stephen Hooper have been awarded a grant from the Translational and Clinical Sciences Institute (TraCS) to study the correlation of brain structure and neurodevelopmental functioning in 12-month-old girls with Turner Syndrome.

Turner Syndrome (TS) is a genetic disorder of females caused by loss of all or part of the second sex chromosome. While a number of scientific studies have found specific structural brain abnormalities and an uneven profile of cognitive strengths and weaknesses in school-age children, adolescents, and adults with TS, there is a dearth of data examining brain structure and function in infants, toddlers, and preschool children.

This project will build upon two existing research studies being conducted at UNC examining early brain development in children with TS by adding a translational component in which concurrent neurodevelopmental functioning of these infants will be examined.

A multidisciplinary team of investigators including Dr. Marsha Davenport, pediatric endocrinologist and expert in Turner Syndrome; Dr. Stephen Hooper, pediatric neuropsychologist; Dr. Rebecca Knickmeyer, experimental psychologist; Dr. Rebecca Edmondson Pretzel, pediatric psychologist; and Dr. Debbie Reinhartsen, speech and language pathologist and their fellows-in-training will conduct neurodevelopmental evaluations, complete histories, and physical examinations in 12-month-old girls with TS in conjunction with structural MRI assessments that are already being performed in the MRI facility at UNC.

Findings from this study should facilitate an increased understanding of the brain-behavior relationships in young girls with TS and, ultimately, clinical management and care for this population at an early age when modest therapeutic intervention could have very large effects.

To learn more contact Dr. Marsha Davenport (mld@med.unc.edu; 966-4435) or Dr. Stephen R. Hooper (stephen.hooper@cidd.unc.edu; 966-5171)



National Fragile X Family Survey

Dr. Anne Wheeler, Assistant Clinical Professor in the Department of Psychiatry, has received new funding from the AUCD (Association of University Centers on Disabilities) through a cooperative agreement with the CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) to expand knowledge about the nature and consequences of fragile X syndrome, both for affected individuals and their families. Information from this project, which builds upon a previous research grant, will be used to inform clinical practice and policy development.

In 2006 the NCBDDD awarded a grant to Dr. Don Bailey and his colleagues at RTI International (a not-for-profit research institute in Research Triangle Park, North Carolina) to develop a data base and conduct a national survey of families of children with fragile X syndrome. The National Fragile X Family Survey project was highly successful, enrolling more than 1000 families who completed the comprehensive survey. Ninety-four percent of the survey respondents indicated that they would be willing to be re-contacted for future surveys about fragile X, making this a unique and invaluable resource for future research.

Building on this resource Dr. Wheeler and Dr. Bailey submitted a successful application to the CDC to form a partnership between UNC-Chapel Hill and RTI International to continue with Phase II of the National Fragile X Family Survey. Melissa Raspa, Ph.D., and Murrey Olmsted, Ph.D., at RTI are also involved in the project.



Dr. Anne Wheeler

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From the Desk of the Director

As you will see by the cover story of this issue of our CIDD newsletter, we are all currently enjoying the afterglow of the dedication of our new building. Of course like any move there has been much work and frustration. But the difficulties of the move seem to be winding down and we are now able to appreciate the advantages that this new building will bring to our Institute.

For those of you that haven't had a chance to see it yet, I encourage you to come by for an informal tour. We would love to see you. The new building is located less than two miles south of the UNC Chapel Hill campus. Amazingly for a University-based facility we have great parking and for the more adventurous among you, we are right on the Chapel Hill 'J' bus line (that leaves every 15 minutes). The new building is only a 15 minute bus ride from the Health Sciences Library!

While we would love to show off our new digs, more importantly to all of us it is clear that this new facility will give us a true center piece to our new Institute. The nine beautiful clinic rooms on the first floor all have accompanying observation rooms for families, trainees and researchers. Many rooms are equipped with dual video cameras for training and research. Trainees can gather in conference rooms on the second floor and manipulate the video cameras to observe clinic examinations or research subjects. Also on the first floor is a large day room available for families attending day long evaluations at the clinic, as well as a play room for kids. This new space is clearly "user friendly" for families and students and will be a wonderful asset for our work going forward.

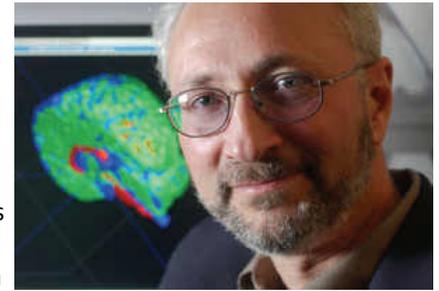
In this new space we also hope to attract local researchers studying individuals with neurodevelopmental disorders. Our dual video cameras in most clinic rooms and observation rooms, as well as other resources e.g., facilities for physical examination, blood drawing, sound-proof audiology assessment room,

set up for electrophysiological assessment (EEG, ERP) and eye tracking, provide state-of-the-art resources for assessment of research subjects. As our overarching goal at CIDD is to integrate the



Joe Piven, M.D. (left) and Jim Hodgins

domains of clinical service, research and training/education, it is our aim to be both the center at UNC that brings together multidisciplinary lines of research as well as the UNC program that closely links findings from cutting-edge research to clinical practice. Also in the works is a plan to use our terrific conference room on the first floor for regular evening meetings with folks in the broader North Carolina community to disseminate research findings and information on state of the art clinical practice. With such a well designed and easily accessible facility we should have no problem in accomplishing these goals.



By Joe Piven, M.D.

As I end this column, I am reminded of the tremendous efforts of many folks to make this a reality. The UNC Medical School Dean's office was critical in our moving forward this plan. Many thanks to Dean Bill Roper, Associate Dean Bob Marriot and his assistant Ms. Tanya Shearin. On the CIDD front, it would have been impossible to conceive of this move without the help of key individuals on our CIDD staff – Brian Wrighten, Tom Gray, Tom Struchen and Ernest Clemmons. The work of our builder/ developer in creating a state-of-the-art facility in 7 months sets a high bar for any such future work in our community. Many thanks to Jim Hodgins for the great job he did as builder and developer. And finally, our sincere thanks to Jeff Low, CIDD Deputy Director, for his involvement and great forethought in every aspect of this endeavor. We are extremely fortunate to have him on our team.

We look forward to many productive years in this new facility – teaching students about all aspects of the care and research relevant to individuals



Left to Right: Brian Wrighten, Tom Struchen, Jeff Low, Ernest Clemons, and Tom Gray

with developmental disabilities; providing services for patients and their families; and, conducting research to discover new insights that will have an impact on the health of those in our community.

National Fragile X Family Survey continued

The original survey sample will be re-contacted for the next survey. By collaborating with the National Fragile X Foundation and the National Fragile X Clinical and Research Consortium, the project will recruit additional families, with a special emphasis on enrolling new families of children diagnosed in the last four years and families from ethnic minority groups.

The project will get input from families, foundations, clinicians, and researchers about the most important questions to ask in the next survey. Likely topics include functional skills and life circumstances (especially for adults with FX), any changes in the age of diagnosis, behavior and social skills, family adaptation, and key public health outcomes of interest to the CDC.

"This project demonstrates the power of involving parents, clinicians, and researchers in a collaborative effort," says Bailey. "The first survey gave us data never before available on such a large number of families. We hope the second survey will be as productive and provide even more useful information."

To learn more about the National Fragile X Family Survey contact program manager Melissa Raspa, Ph.D. 1-866-860-5229; mraspa@rti.org

Leadership Grant Adds Autism Component

The Carolina Institute for Developmental Disabilities is home to one of only three leadership grants in the U.S. funded by the Maternal and Child Health Bureau (MCHB) for "Leadership in Pediatric Communication Disorders." According to Project Director, Dr. Jack Roush, "we work closely with three other MCHB-funded leadership grants at UNC based in Public Health, Social Work, and NC-LEND, that together comprise UNC's Maternal and Child Health Leadership Consortium." The MCHB grant for Pediatric Communication Disorders was originally funded in 2008 to provide leadership education in early identification and management of hearing loss. In 2009, MCHB appropriated additional funds for grantees interested in adding a leadership component in the area of autism. Roush notes "the resources and expertise we have in autism at UNC made this a logical area of expansion for our leadership grant. We were very pleased to receive the additional funding and are grateful to Dr. Linda Watson, from the

Division of Speech and Hearing Sciences, for mentoring the first two students funded on the autism component, Ashley Brasfield and Ashley Sholtis. Both are graduate students in UNC's M.S. program in speech-language pathology (see photo).



Welcome LEND Trainees

The CIDD's interdisciplinary and clinical training initiatives are funded through the Maternal and Child Health Bureau's [Leadership Education in Neurodevelopmental and Related Disabilities](#) (LEND) Program. This unique program has been funded continuously since 1970 and we are excited to welcome the following trainees for the 2010-2011 academic year:

| | |
|------------------------|---------------------------|
| Alexandra O'Dell | Audiology |
| Brittany Richardson | Audiology |
| Danielle Sturgeon | Audiology |
| Jennifer Sundberg | Audiology |
| Kate Bowman | Audiology |
| Lena Kyman | Audiology |
| Melissa Aldana | Audiology |
| Mallory Baker | Audiology |
| Megan Kovac | Education/ Psychology |
| Catherine Wilson | Health Administration |
| Katherine Shattuck | Nursing |
| Emily Furgang | Occupational Therapy |
| Erin Wentz | Physical Therapy |
| Devon Hartford | Psychology |
| Ashley Durkee | Psychology |
| Kira Fisher | Secondary Education |
| Carly Dragan | Speech-Language Pathology |
| Katie Collins | Speech-Language Pathology |
| Keely Broderick | Speech-Language Pathology |
| Melanie Schrage | Speech-Language Pathology |
| Samantha Schlegelmilch | Speech-Language Pathology |

The CIDD Dedicates New Building continued



building provides space specifically designed for optimal patient care. Each of the nine clinic rooms has an observation room for family members to participate and observe evaluations. The family break room provides needed support during day long evaluations and the community location provides easy access and parking.

The space is also specifically designed for the interface of multiple disciplines – genetics, neurology, pediatrics, psychiatry, psychology, speech-language pathology, audiology, occupational and physical therapy, nursing, nutrition, education and social work – all under one roof, to enable the integration of complex areas of expertise required for optimal care of individuals with developmental disabilities throughout the lifespan.

It is a state-of-the-art facility for clinical research, including data collection for numerous federally funded clinical research studies. The new clinic rooms include equipment for monitoring all aspects of behavior (e.g., video cameras, measurement of brain electrophysiology, eye tracking).

The new space will also enhance the clinical training of future service providers in a range of clinical services and education, as well as policy makers, to expand the capacity of the state of N.C. to provide the highest quality of life to individuals with developmental disabilities and their families.

Come visit our new building at **101 Renee Court in Carrboro, NC 27510.**

Official Name Change for NDRC and CDL

The Center for Development and Learning (CDL) and the Neurodevelopmental Research Center (NDRC) are now completely integrated into the Carolina Institute for Developmental Disabilities and will no longer use their previous names. Although the CDL and NDRC names are history now, the services that these organizations have provided in the past are continuing and expanding.

The NDRC and CDL bring together three developmental disabilities programs of national significance – the Intellectual and Developmental Disabilities Research Center (IDDRC), the University Center of Excellence on Developmental Disabilities (UCCED), the Leadership Education in Neurodevelopmental Disorders (LEND) – to become one of the largest and most comprehensive programs in developmental disabilities in the country. Together these programs serve 1,000+ patients per year, train 200+ students and 2,000+ community members, link 14 departments within UNC, and support 100+ research projects by 50+ scientists bringing in over \$35 million in new research funds per year.

The CDL and NDRC have a more than 40 year history of providing services and conducting research to benefit individuals with developmental disabilities and their families and as a part of the larger CIDD organization, their impact will be much greater.

Please visit the CIDD website to learn more. www.cidd.unc.edu

CIDD at the National AUCD Conference

CIDD Faculty members participated in the [Association of University Centers on Disabilities](#) (AUCD) annual conference October 30—November 3rd of this year. The AUCD is a network of interdisciplinary centers advancing policy and practice for and with individuals with developmental and other disabilities, their families, and communities. Click on the titles below to view a PDF of the poster or presentation.

- [Analysis of National Core Indicators Data: Does Healthcare Vary According to Type of Funding?](#) Authors: Debbie Reinhartsen, Becky Pretzel, Kristine Kelsey, Rebecca Greenleaf-Bailey, Karen Luken, Maria Fernandez, Adolph Simmons, Terrie Qadura
- [North Carolina's Autism Alliance: Connecting and Enhancing an Early Intervention System of Care.](#) Authors: Deborah Carroll, Stephen Hooper, Lauren Turner Brown, Rebecca Pretzel, Rob Christian
- [Building an Alliance for Postsecondary Education.](#) Authors: Donna Yerby, Deb Zuver
- [The Fragile X Research Registry: Opportunities for Collaboration With and Between Networks.](#) Authors: Leonard Abbedutto, Renee Clark
- [The Effects of Interdisciplinary Training on MCH Professionals, Organizations, and Systems.](#) Authors: L. Margolis, A. Rosenberg, K. Umble, L. Chewning, J. Dodds, M. Milano, K. Rounds

New Hearing and Development Clinic continued

by providing a multidisciplinary diagnostic evaluation for infants and young children with hearing loss. The primary purpose of the clinic is to determine if the child is experiencing developmental deficits, and if so, to provide recommendations for follow-up and treatment. Typical referral concerns include speech and language development, processing difficulties, cognitive delays, or questions regarding socialization, communication, and sensory function. This is the first multidisciplinary team of its kind in North Carolina.

Through an in-depth assessment process the HDC team works to create a comprehensive intervention plan for families and caretakers. The team also communicates with local service providers to assist with locating resources available through the NC Department of Public Instruction and other agencies. The team is coordinated by audiologist Jackson Roush, Ph.D. and team members include Martha Mundy, AuD (Audiology); Jean Mankowski, Ph.D. (Psychology); Kathryn Wilson, M.A., LSLC Cert.-AVT (Speech-Language Pathology); and Donna Yerby, Ph.D.(Education). CIDD Speech-Language Pathologist Margaret DeRamus, M.S., provides consultation when there are concerns related to autism. Other CIDD specialists are available as needed.

An interpretative conference with the family is provided at the conclusion of the multidisciplinary assessment. This is followed by a detailed report that explains the results of the evaluation and strategies for addressing the child's needs. Regional and statewide resources are also provided, and the team stays in touch with the family to make sure their needs are being met.

An important component of the Hearing and Development Clinic is the education of graduate students involved in CIDD's Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program. Students from the LEND disciplines participate in the interdisciplinary team under the mentorship of CIDD clinicians. To learn more about the Hearing and Development Clinic, contact Dr. Roush at jroush@med.unc.edu or telephone 919 966 9467.



CIDD psychologist Jean Mankowski (right) and psychology intern Tammy Dawkins from McGill University administer a test of cognitive function to a four-year-old.

Announcements:

- **Young Investigator Award:**

CIDD Investigator, Ben Philpot, Ph.D., was among 5 researchers honored by NARSAD for their outstanding contributions to mental health. Dr. Philpot and the other awardees were chosen among more than 3,000 young researchers funded by NARSAD Young Investigator Awards. Dr. Philpot's work identified how the molecular composition of receptors shapes memory formation and the wiring between brain cells. [Click here](#) to learn more.



- **Jim Bodfish, Ph.D., CIDD's Associate Director presents:**

→ Dr. Bodfish gave a plenary session entitled *Autism: Advances, Current Challenges, and Future Directions*. At the NADD's 27th Annual Conference Nov. 3-5, 2010 in Seattle, WA. The [NADD](#) is an association for the benefit of persons with developmental disabilities and mental health needs.

→ Dr. Bodfish will present at the 5th Annual ABAI Autism Conference: New tools for Translating Science to Practice on January 28-29, 2011 in Washington, DC. The Association for Behavior Analysis is International's ([ABAI](#)) mission is to contribute to the well-being of society by developing, enhancing, and supporting the growth and vitality of the science of behavior analysis through research, education, and practice. Dr. Bodfish's presentation is entitled Repetitive Behavior in Autism: Brain-Behavior Relationships.



- **CBS News features CIDD IBIS Study:**

A video featuring CIDD's [Infant Brain Imaging Study \(IBIS\)](#) and its work to gather data in order to provide important information regarding early brain development as well as genetic and environmental factors associated with autism is highlighted on the UNC Healthcare website. [Click here](#) to see the video which includes interviews from our director Dr. Joseph Piven, CIDD Investigator Heather Hazlett-Cody, Ph.D., and the Denesen family participating in the study.

- **NC Post Secondary Education Alliance Newsletter :**

[Click here](#) to learn about examples of real-world changes effected through the NCPSE that range from public awareness, program development, capacity building, technical assistance, and the beginnings of policy change.

Send us your comments:

We would love to hear from you if you have comments about our newsletter, or if you would like to be added to our newsletter list!

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

Drop us a line: info@cidd.unc.edu.

Many thanks to our newsletter article writers and editors:

Jack Roush, Keath Low, and Julia Tarr

Your Support

For more than 40 years, the programs of the Carolina Institute for Developmental Disabilities have provided innovative, high-quality clinical, research, and training activities supporting individuals with developmental disabilities.

The population of our state and nation is growing, and the disability community is growing as well. Children are being diagnosed with developmental disabilities such as autism at an exponential rate. Often, families dealing with a loved one with a disability can feel overwhelmed and need a place to find real answers. Through innovative research that improves practice and enhances education, we will find solutions.

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

A gift to the Carolina Institute for Developmental Disabilities is an investment in the lives of thousands and in the future of our communities. Join us by giving today.

To make a donation by credit card, please visit the Medical Foundation of North Carolina's gifting page and choose "Carolina Institute for Developmental Disabilities." [Click Here.](#)

To make a cash donation, please send your check to: The Carolina Institute for Developmental Disabilities, University of North Carolina at Chapel Hill CB# 7255, Chapel Hill, NC 27599-3366.

Contact: Julia Tarr at (919) 966-7519 or julia.tarr@cidd.unc.edu to discuss your giving options.