

## Developments and Upcoming Events

### NEW NORTHWESTERN INSTITUTE FOR DEVELOPMENTAL SCIENCES

This December, Northwestern announced the establishment of the Institute for Innovations in Developmental Sciences (DevSci), which brings together an engaged developmental sciences research and training community, including more than 100 interdisciplinary researchers and clinicians at NU whose scientific activities are focused on child development and its implications for lifespan health and well-being, with an eye towards providing pipelines for rapid translation from discovery to clinical application. Our lab plays a large role in DevSci, and Dr. Losh also co-directs the Institute's Center for Training, which focuses on supporting and educating the next generation of clinician scientists studying child health and development. The Institute will provide important support for researchers, clinicians, and families and their communities by channeling resources into research into the biological and environmental influences on neurodevelopment, including intervention and education.

### NEW MEMBERS OF THE NDL

In addition to the new studies in the lab and important new University initiatives, we're excited to welcome our new doctoral student, Molly Winston, to the lab. Molly joins our team of 6 existing doctoral students and three full time staff members who lead our projects. Molly brings with her terrific research experience focused on understanding how arousal (or the body's automatic response to the external environment) might relate to clinical features of autism and fragile X syndrome, as well as associated features like anxiety. We are so happy to welcome her to the NDL!



### COMING TO A CITY NEAR YOU!

Members from the Neurodevelopmental Disabilities Lab regularly visit Iowa and areas throughout the Midwest to share information about our research. Our group made several trips to Iowa this fall and loved meeting with community members at different events, including Farmer's Markets and local festivals. We are grateful for the involvement and support to all of our study participants, and our research team looks forward to visiting Iowa again soon!



### CONNECTIONS TO THE UNIVERSITY OF IOWA

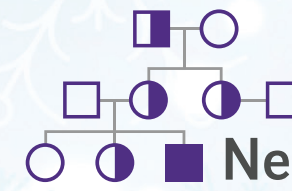
Dr. Molly Losh gave a series of presentations at the University of Iowa in October and December, discussing findings from our research studies with members of the Department of Pediatrics and the Center for Disabilities and Development. Discussions focused on the critical role that Iowans are playing in making important discoveries about autism and fragile X syndrome. Physicians and researchers at the University of Iowa share our goal at the NDL of improving the health and independence of individuals with developmental disabilities and we feel privileged to have their support in working with families throughout Iowa on our research.

### NATIONAL PEDIATRIC DEVELOPMENTAL DIFFERENCES FORUM

Our research lab was proud to help sponsor "The National Pediatric Developmental Differences Forum: A thought leadership initiative for the advancement of relationship-based therapies". The forum took place on October 21st and 22nd and featured a number of researchers and clinicians who work with individuals with autism, including our own Dr. Molly Losh, who alongside our clinical collaborators Amy Levin and Jordan Sadler, spoke about our research findings that document different strengths in autism, and how these abilities appear genetically based, and often run in families. Other featured speakers included Dr. Barry Prizant, and John Elder Robison, who spoke about the lived experiences of individuals with autism. The event had a great turn-out and provided important perspectives of clinicians, researchers, and individuals and families, in order to better support collaborations that will help translate research findings to clinical practice.



# Happy 2017 from the NDL!



**Neurodevelopmental Disabilities Lab**  
NORTHWESTERN UNIVERSITY

We want to wish you a happy and healthy 2017 from all of us at the Neurodevelopmental Disabilities Lab at Northwestern University, along with our collaborators at the University of North Carolina-Chapel Hill, Rush University, St. John's University, and the University of Iowa. Our research would not be possible without your involvement and support, and we are so grateful for your participation in our research studies! The time and effort that families devote to research participation is helping us to make important discoveries on a number of fronts, and has resulted in several new publications, new federal funding for our research studies, and new collaborations with networks of professionals and families who are invested in improving support for families. In this 2017 newsletter, we provide an update on new research findings and events from our research team, as well as new opportunities for involvement in our research. We hope you enjoy this update!

Sincerely,  
The NDL Team



### Find us online!



This summer we launched a new lab website where families can stay up to date with news in the lab, with pictures and summaries of recent events, and information on new findings and opportunities to participate.

Visit [www.familystudy.northwestern.edu](http://www.familystudy.northwestern.edu) and our Facebook page [www.facebook.com/NDLfamilystudy](https://www.facebook.com/NDLfamilystudy) for more information!



## Upcoming Publications from the NDL

Several new findings from our research studies will be published in 2017. First, we are proud to have contributed the upcoming book, *Research in Clinical Pragmatics, Series: Perspectives in Pragmatics, Philosophy & Psychology*. In our chapter (Martin, Lee, & Losh) we discuss the communicative strengths and challenges in autism, fragile X syndrome, and Down syndrome, with an eye towards key abilities that should be targeted in interventions. This important text is intended to serve as a resource for clinicians and families.

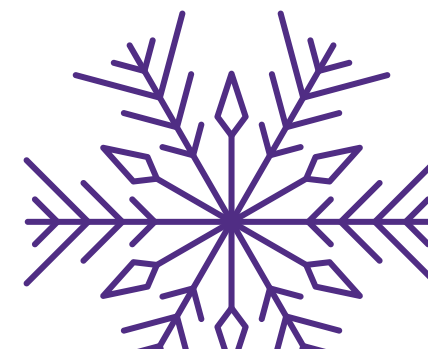


Our findings will also be published in several manuscripts that will be posted on our website in the coming months. One upcoming article to appear in the journal *Autism*, examines narrative, or storytelling ability, in individuals with autism compared to individuals without autism. We used two different methods: having trained researchers measure different aspects of narrative ability (e.g., talking about characters thoughts and feelings, connecting events with an overarching theme), and applying an automated tool to characterize the quality of the narratives. We found that individuals with autism demonstrated difficulty using different grammatical devices, such as the use of descriptive phrases for making sentences longer or linking multiple phrases together, and explaining characters' thoughts and emotions to create connected narratives. Further, the automated tool also distinguished narratives of individuals with autism from those of the comparison group and strongly related to researcher

ratings of narrative content and quality. These findings highlight specific aspects of narrative that are most challenging to individuals with autism, which will serve as important intervention targets, and also highlight the potential applicability of a new tool to automatically characterize narrative abilities, and how these skills can be meaningfully influenced in intervention.

Another study, to be published in the *Journal of Neurodevelopmental Disorders* examined profiles of development and change in children with autism and children with fragile X syndrome over several years. We found that that symptoms of autism increased in children with fragile X with age, and that challenges in social communication showed strong overlap in the autism and fragile X groups. These findings help to pinpoint how the *FMR1* gene may importantly relate to a key feature of autism (social communication), and that this arena of development warrants specific attention in diagnosis and intervention planning in both groups.

Among our other new publications, one of the most significant presents findings from the first stage of our NIH-funded *Family Genetic Study of Language in Autism*, to be published in the *Journal of Autism and Developmental Disorders*. This publication represents over 5 years of work, where we visited families throughout Iowa for research assessments, resulting in important findings that highlight key childhood academic profiles in parents that predict features of autism in the next generation. That is, patterns of development in key academic domains of math, reading, and language in parents, assessed during childhood, and archived and accessed with permission from these parents, predicted the types and severity of symptoms that their children with autism showed many years later. These findings are incredibly exciting in showing how the genes that relate to autism are expressed among people without autism in subtle language and cognitive profiles, and might be used in the future to understand autism risk in families. This work also served as the basis for the newly funded second stage of this study, which was just awarded from the National Institutes of Health. Please watch for more information on this study as we begin recruitment in 2017! We're also conducting a related NIH-funded study of childhood academic profiles of women with the *FMR1* premutation, and will update you on those findings in our next newsletter. To learn more please check out our website, and see "New Research Studies" in this newsletter.



## New Research Studies

### FAMILY CONNECTIONS: A 5-YEAR MULTI-GENERATIONAL STUDY OF GENETIC MARKERS OF AUTISM

We received a 5-year grant from the National Institutes of Health to continue our Family Genetic Study of Autism, which began in 2010. In the first phase of this study, we found evidence that subtle profiles of childhood academic performance in parents predicted features of autism in children in the next generation. These findings will be published in the *Journal of Autism and Developmental Disorders*, and served as the basis for the next phases of the study, which will explore cross-generational predictors of autism by including grandparents as well as parents and individuals with autism. In this study we hope to understand how the genes involved in autism can also influence traits like personality and language, along with specific cognitive profiles in people without autism, and may also relate to unique strengths. The study also examines how brain activity (measured easily while participants watch a movie), may relate to these different profiles. Please watch for more information on this exciting new project!



### THE NDL IS PARTICIPATING IN LARGE NIH STUDY OF ENVIRONMENTAL RISK FACTORS IMPACTING CHILD HEALTH

Dr. Losh is an investigator on a \$157 million NIH initiative, *Environmental Influences on Child Health Outcomes*, or ECHO, which joins researchers throughout the country to identify key environmental factors that impact child health, including risk factors for autism and related conditions. Northwestern serves as the lead site for the ECHO study's Patient Reported Outcomes Core, which will develop key exposure and health assessments and capture the voices and experiences of children and their families to better understand how exposure to different environmental factors may have impacted the health and development of children.



You can read more about this major NIH initiative here: <https://www.nih.gov/news-events/news-releases/nih-awards-more-150-million-research-environmental-influences-child-health>