University of South Carolina Neurodevelopmental Lab





Mia and Evie Willis – adorable participants in our study!

It is almost hard to believe how far the USC Neurodevelopmental Disorders Lab has already come this year, but with the support of our incredible participants and hard-working team, it is no wonder that anything is possible! We are making strides in our research efforts through our NIHfunded longitudinal studies while having the opportunity to follow the development of our participants across the years.

This year, we not only welcomed new participants into our studies, but we also had the pleasure of witnessing our participants' families grow as they welcome little additions of their own. None of our research would be possible without the continued support of our participating families, so we would like to thank you and share a little more about what is new and brewing in the NDD Lab!

We are Recruiting!

Do you know families who may be interested in our projects?



We are still recruiting families with children 3 years and below who fall into one of the following categories:

- Diagnosed with Autism Spectrum Disorder and a developmental
- Have an older sibling diagnosed with autism
- Diagnosed with Fragile X Syndrome or FMR1 premutation
- Diagnosed with Down Syndrome
- Typically developing children
- Families who are expecting the birth of a child who may fit any of the above criteria

Spring Highlights

- Dr. Jane Roberts gave a talk at UC Davis' Distinguished Lecture Series on April 12th 2017 entitled Bio behavioral Profiles in Infants with Fragile X Syndrome: Emergence of Autism and Anxiety in Fragile X Syndrome.



- Graduate students Jordan Ezell and Carla Wall have been accepted to the Center for Healthcare Quality (CHQ) Junior Scholar Program.

- Dr. McPartland from Yale University will give Dr. Jane Roberts attended the National a colloquium speech on July 25th entitled Fragile X Advocacy Day in Washington D.C.. Electrophysiological Recordings in ASD Research at the Institute advocates for the Mind and Brain.
- Lab members presented their research at various sites including the Gatlinburg Conference on Research and Theory in Intellectual Disabilities, the International Meeting for Autism Research in San Francisco, and USC's Discovery Day.
- Chandler Knott, Allison Vittes, Nicole Vonada, and Hannah Thomas are all USC undergraduates who were awarded a Magellan grant from USC to fund their Here, Dr. Roberts is pictured with Dejan undergraduate research.

Brain Parents, family members, and selfliving with fragile X are encouraged to participate in this annual event and make their voices heard.



Budimirovic M.D., medical co-director of the Fragile X Clinic at Kennedy Krieger Institute, as well as Tracy Stackhouse, and Sarah ("Mouse") Scharfenaker, the cofounders of Developmental FX in Denver Colorado.

- -The USC College of Arts and Sciences published a news story on our recent work entitled <u>Piecing</u> together the Autism Puzzle. It highlights the work of Dr. Jane Roberts, post-doctoral fellow Abigail Hogan and recent graduate Nicholas Poupore.
- -Dr. Jane Roberts is spearheading a statewide effort to promote research in autism and other neurodevelopmental disorders. The organization entitled, South Carolina Autism and Neurodevelopmental Disorders

 Consortium (SCAND), is comprised of experts from Greenwood Genetics Center, Palmetto Health, USC Greenville, USC Columbia, Clemson and the Medical University of South Carolina. Their first research meeting is planned for this fall at the USC Alumni Center.
- -We are excited to welcome our newest postdoctoral fellow, Elizabeth Will, to join our lab in July! Dr. Will completed her PhD in Applied Developmental Science at Colorado State University. Her research will focus on vulnerabilities and psychophysiological mechanisms contributing to differential outcomes for individuals with fragile X syndrome.
- -We will also be welcoming our newest graduate student, Conner Black, who received his bachelor's degree from Syracuse University where he investigated multisensory integration in both typically developing children and children on the autism spectrum. He will be enrolled in the School Psychology Ph.D. program this fall under the mentorship of Dr. Roberts.
- -With the help of our participant families, we have had been able to publish the results of many studies in prestigious peer-reviewed journals. In 2016, we put out 10 publications and in 2017, we have already published six research studies with more in the submission process. Don't forget to check the <u>publications page</u> of our website for our latest research findings!

This Spring, with the help of videographer John Allen, we were able to create videos which introduce everyone to what we do here at the NDD Lab. These were really fun to make and we hope that it helps to prepare our families for what to expect during assessments!!

Click <u>here</u> to view our new NDD Lab Introductory Video in which we explain the most common components of our assessments. Thank you to AJ and Lucinda, our NDD stars!

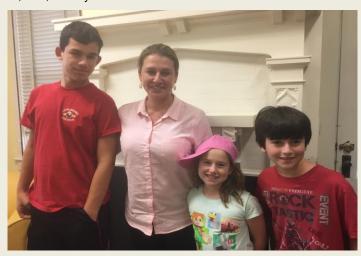


Click <u>here</u> to view our new NDD Lab Introductory video in which we walk you through what to expect during an electroencephalogram (EEG)!



Focus on Participant Family

As mentioned numerous times, we could not be successful researchers without the dedication of our families, so for each newsletter, we would like to focus on the stories of the participant families who have meant so much to us throughout the years. This June, we were pleased to have the Edelen family come to the NDD Lab. Pictured below are Jayden, Dana, Ava, and Rylan.



Dana Edelen is from Romania and moved to the UNC Chapel Hill area in 1994 when her mom started graduate study there. At that time, Jane Roberts was a graduate student and Dana's mother, Irina, was actually the teaching assistant for one of Jane's courses. Little did both of them know that their lives would continue to intersect in the future. When Dana was only 18 years old, she was diagnosed with hodgkin's lymphoma and had to undergo extensive treatment to overcome this disease. Thankfully, she beat the cancer and she and her husband started a family in 2003 with the birth of Jayden! He was such a happy baby but at about 6 months old, Dana noticed that he was not reaching his developmental milestones. A research group at UNC suggested that she get Jayden tested for fragile-X and the results showed that Jayden had FXS. That was when her mother, Irina, told her to go see Dr. Roberts because she knew Jane was doing research on fragile X. At first, Dana was worried that Jayden would not be able to walk and would have serious handicaps but her fears were not realized. Jayden has grown to be a warmhearted teenager who looks out for his younger siblings and always has a bright smile to greet everyone he meets. Jayden is able to read and has some good friends. His siblings are Rylan, who has the fragile-X premutation, and Ava, who is unaffected. Rylan is academically gifted with a daredevil streak (we won't mention how many times he has been to the emergency room) and Ava is an expert soccer player with musical aspirations and a love for animals. We have thoroughly enjoyed watching them grow throughout the years and we are so grateful that they have been a part of our infant/preschool study since 2010! It is families like this that make us dread the day the study will come to an end.



GENETICS

The newest component of our infant and preschool assessments involves collecting small blood samples to analyze genetic components using cutting edge technology. Mothers and children currently enrolled in our studies can opt to schedule one time blood draws to assist us in this endeavor. We offer additional compensation for these optional components and we make participating as convenient as possible.



A new online study called SPARK is looking to collect and analyze DNA samples using a saliva collection kit to further understand the roles of specific genes in autism development. The study is looking to recruit anyone involved in the autism community, including adult and children diagnosed with autism, and their biological parents and siblings. If you are interested in this free online study, register for SPARK at

www.SPARKforAutism.org/musc, or visit their website for more information.



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