



Spring Newsletter

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Spring Greetings

Dear Families,

Happy Spring and Autism Acceptance
Month on behalf of our team! Thank you
for your continued support and
participation in the research we are
working on together. It would not be
possible without you. We love having you
at our lab! We hope you and your family
have a joyful spring filled with fun
activities, laughter, and sunshine!

With warmest regards, Susan Faja and the Faja Lab team







IDEA: Individual Development of Executive Attention

We are excited to announce that the IDEA Study is wrapping up enrollment. Over 280 families are currently enrolled, and we will be following the development of these children for two years. In collaboration with early intervention programs and primary care providers, the IDEA clinical research team provided 48 first-time autism diagnoses throughout the study. We are thankful to have been able to provide this information to families and for the privilege of working with so many incredible families and children. In the past few months, we have begun to examine our preliminary findings from the first time point. We have submitted several poster abstracts to the International Society for Autism Research (INSAR) Annual Conference, which will take place in Stockholm, Sweden, in May 2023. We also recently received a generous donation from a private donor to continue this work for the next few years. Our research team will be in touch to make sure participation in your family's next on-site visits is as easy as possible!

ABC-CT: Autism Biomarkers Consortium for Clinical Trials

The ABC-CT project started in 2015 with the goal of developing better ways to measure social function for children on the autism spectrum. Ultimately, we hope this will lead to a more precise evaluation of new interventions as we continue to build on this research. **399 children and their families contributed to this effort so far.** We are so grateful to these families for their participation.

To date, we have evaluated two tools for measuring social function: electroencephalography (EEG; a measure of brain function) and eye tracking (a measure of attention). You can read more about the consortium's EEG and eye tracking measures in recently published articles via the American Journal of Psychiatry and Molecular Autism. These studies suggest that EEG and gaze toward faces may be reliable tools for identifying clinically meaningful subgroups within the autism spectrum, which can lead to better testing of interventions designed for the specific needs of subgroups. As a result of this work, the first two biomarkers evaluated by the ABC-CT study were accepted into the Food and Drug Administration's biomarker qualification program.

In 2020, we received additional funding from the National Institutes of Health to continue our research with the children who first participated. A total of 256 participants, ages 8 to 16 years, returned for the follow-up study across the consortium at Boston Children's Hospital, Yale, Duke, UCLA, and UW. Some families participated up to 4 years after their final visit for the main study! **We would like to extend a huge thank you to all families who returned for their commitment and enthusiasm for advancing this important science.**

The follow-up study will provide critical information about how the tools being tested predict long-term social development for children and adolescents. In October, Dr. Faja and researchers from the consortium presented preliminary results from the follow-up study at a meeting held in Seattle. We examined the impact of COVID-19 as well as some of the clinical changes and outcomes. We are moving quickly toward publishing some of these findings and look forward to sharing these results with you in the coming year.

We are currently enrolling 6- to 11-year-olds with a diagnosis of autism or with no clinical concerns. For interested families, please reach out to us at <u>ABC-CT@childrens.harvard.edu</u> to learn more.



CRUSH Study: Competence in Romance & Understanding Sexual Health

The CRUSH study asks autistic adults about their sexual history and knowledge to understand how to better support the development of intimate relationships. In 2022, we published a paper in the *Journal of Autism and Developmental Disorders* that described the relationship between pragmatic language skills—or how we adapt our communication to meet the demands of the social situation—and the ability to describe concepts related to sexual health. For autistic adults, pragmatic language ability, but not the ability to recognize true or false statements about sexual health, predicted the ability to explain sexual health terms above and beyond general verbal ability. A similar pattern was found in a group of adults without a diagnosis of autism, suggesting that the general ability to adapt language for the needs of the communication partner is an important part of being able to communicate about sexual health. This is important because it suggests that pragmatic language skills may support the ability to have effective discussions with healthcare providers or sexual partners.

In September 2022, we received a pilot grant to test the CRUSH curriculum we have been developing. This project will focus on providing the sexual health curriculum to a small group of autistic adults to evaluate whether the intervention is feasible and acceptable.

We are also working with UC Davis and Colorado Children's Hospital to extend Project CRUSH to learn about the intervention needs of autistic teenagers. Teen CRUSH will evaluate the sexual health and romantic goals of 15- to 17-year-olds.

If you are interested in joining either CRUSH or Teen CRUSH, don't hesitate to contact ProjectCRUSH@childrens.harvard.edu for more information.



Project KISS: Key Intimate Social Skills

We are excited to announce that we are beginning a new NIH-funded study, Project KISS, for autistic and non-autistic adults between the ages of 18 and 35 years. Project KISS is a collaboration with the Crehan Lab at Tufts University to develop and test new measures of social skills that are needed for romantic relationships. This study will assess behavioral and physiological tools to measure heart rate and attention during social tasks or while watching images and videos showing social interactions. If you are interested in joining KISS, please email ProjectKISS@childrens.harvard.edu for more information.



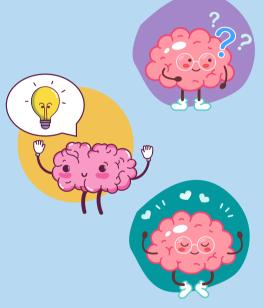
L16HTHOUSE Study

The Faja Lab is collecting EEG responses from participants in a clinical trial called L16GHTHOUSE. This clinical trial is investigating an experimental medication for treating speech, motor, learning, and other developmental delays in children and adolescents with 16p11.2 deletion syndrome. The Faja team will help evaluate whether the medication produces changes in brain function during tasks such as listening to speech sounds or learning visual information. For more information about L16GHTHOUSE and the four participating research sites, please visit https://www.lighthouse16p.com.



Understanding Anxiety Study

Over the past year, the anxiety study team has worked with 19 children and their families to learn more about the potential biological indicators of anxiety among young autistic children. This is important because young children may not be able to describe their anxiety verbally even though it may impact their ability to participate in activities at home or at preschool. To test the tools for measuring anxiety, preschoolers ages 3 to 6 join us in the lab and we collect information about how they respond while playing games, looking at pictures, and trying a taste of juice. While "dressed up like a robot," we use special sensors to measure the amount of sweat on their hand, their heart rate, and their brain responses. We hope that this information will allow us to better understand how anxiety may present itself and what tools we can use to better identify anxiety in young children. Recruitment is wrapping up soon! If you recently participated in the IDEA study and want to learn more, please reach our study team at ideastudy@childrens.harvard.edu.







the GAMES and EASY Projects



Executive function, which is a set of thinking skills that includes stopping unwanted responses, being flexible, and remembering information needed to solve problems, is a challenge for many children on the autism spectrum. The GAMES study tested whether executive function could be improved with a computerized executive function training program under the guidance of a coach who reinforced the use of executive function skills. Seventy children with autism spectrum disorder from 7 to 11 years of age participated in the study. They were randomly assigned to receive training or to a waiting group. All children assigned to training completed the program and families generally reported the experience was positive. Brain responses of the training group changed following training, but not for the waiting group during a similar time period. However, children who received training did not exhibit behavioral changes for lab-based tasks. Parents reported that neither group showed a significant change in their broad use of executive function in other settings. Yet, children who received training were reported to have fewer restricted and repetitive behaviors following training. These initial findings suggest that brief executive function training activities are feasible and may improve some functioning of school-aged children on the autism spectrum. These findings were published in Autism in 2021.

Understanding both for whom and how interventions work will help us provide personalized care to children on the autism spectrum. Co-occurring mental health challenges may affect how much autistic children benefit from intervention. We further examined information from the GAMES Study to assess whether: (1) cooccurring attention-deficit/hyperactivity disorder (ADHD) features or anxiety features, measured before the training began, affected how much children benefited from executive function training. In other words, we asked, "For whom is training effective?" We also explored whether: (2) children's brain-based changes in executive function predicted their performance in everyday life (e.g., parent report on a survey). This is a step toward asking, "How is training effective?" We found that training improved children's inhibition ability, but only for children with clinically significant ADHD features. While many children in our sample also had anxiety features, we found that anxiety levels did not affect how well the training worked. Finally, for children in the training group, changes in brain activity during a task that measured the ability to notice conflicting information corresponded with changes in children's repetitive behaviors. These findings were published in Autism Research in 2022.

Participate in Research

Studies currently recruiting:

Anxiety Study

 3 to 6-year-olds on the autism spectrum who are participating in the IDEA Study

For more information, contact IDEAstudy@childrens.harvard.edu.

Autism Biomarkers Consortium for Clinical Trials (ABC-CT):

- 6 to 11-year-olds with an autism diagnosis
- 6 to 11-year-olds with neurotypical development

For more information, contact ABCCT@childrens.harvard.edu.

Project CRUSH and teen CRUSH

- 18- to 26-year-old autistic adults who use spoken language to communicate
- 15- to 17-year-old autistic adolescents who use spoken language to communicate

For more information, contact <u>ProjectCRUSH@childrens.harvard.edu</u>.

Project Kiss

• 18- to 35-year-old speaking autistic and non-autistic adults

For more information, contact <u>ProjectKISS@childrens.harvard.edu</u>.







Neuroscientist in Training

Years ago, when Dr. Faja was in second grade, she met an amazing woman who studied butterflies and moths. This kind of scientist is called a lepidopterist. Dr. Faja took classes with the lepidopterist and learned how to tag butterflies to track their migration. Her family raised caterpillars in containers on the kitchen table to learn about their development and biology. One day while visiting the Ann Arbor Hands-On Museum, Dr. Faja shared some of the things she had learned with the scientists at the museum, and they invited her to come give a talk to other children at the museum to share her knowledge.

Do you have something that you love to learn about? Maybe you like to carefully watch things or take them apart to learn how they work. Or maybe you like to draw pictures or write notes about things you notice around you. These skills are the same skills that we use to learn how brains develop and grow and to learn about our patterns of behavior.









use it or lose it!

You probably know that exercise makes our muscles stronger. Muscles help our body move, including walking, running, climbing, jumping, eating, drawing, talking, and singing. We have different muscle groups, and each group is responsible for different movements. When we do not use our muscles often, they become weak, and when we challenge them, we build stronger muscles. Stronger muscles lead to stronger bodies.

Did you know the same rule applies to your brain? Brains are made of neurons. Neurons are messengers of information. They interact with their neighbor neurons, send information to each other, and create pathways for sending information between different parts of the brain and between the brain and the rest of the body. Different groups of neurons are responsible for different skills, feelings, and activities. There is nothing that we do that doesn't involve neurons. What we think, feel, do, and experience is made possible by these connections between neurons.

Neurons are not muscles, but the same rules apply to them. Suppose you challenge your brain by learning new things and experiencing different activities. In that case, you make the new connections between neurons more robust and efficient. Can you think of different ways you are challenging your brain at home or in school?

You can learn more about neurons and the brain at: www.ninds.nih.gov/health-information/public-education/brain-basics

You can also find games, puzzles, information, and activities related to brain science and research at: www.nimh.nih.gov/health/publications/imaging-listing

Science at-



Monster Marshmallow Experiment

what you need:
marshmallows (big and small)
microwave oven
microwave oven-safe plate
toothpick (optional)
food coloring/ chocolate syrup (optional)
adult supervision!



Place marshmallows on a plate and draw eyes and mouths on them with a toothpick and chocolate syrup or food coloring. Then place the plate in the microwave oven for 60 seconds and watch your marshmallows grow into massive monsters or cute and cuddly giants. Be careful when removing the plate from the microwave oven since it may be hot. Watch the monster marshmallows shrink as they cool down, and then before enjoying your treat, explore it a little more. Stretch it, twist it and examine the texture. How are they different from your regular marshmallows?

Write down your observations. What did you see?
Write down your guesses. What was the reason behind the
changes in marshmallows?
Can you think of the next steps in your research? How can you experiment differently with marshmallows and heat?

Celebrating Neurodiversity





From left to right: Diamante, Aiko, Maryam, Nasim, Sheena, Gina, Susan, Karen, Doo-yun, Matt, and Stephen.

Team members who are not present in this photo: Sebastian, Maddie, Aanya, Kate, Devon, Erin, Mimi, Kohrissa, Yohana, Katie, Shruthi, Oumou, Melinda, and Devangi.

April is Autism Acceptance Month. At Faja Lab, we embrace and celebrate neurodiversity every day! The rainbow spectrum of colors is often associated with autism to represent the range of abilities and diagnoses within the autism spectrum. We dressed as a rainbow last week to kick off Autism Acceptance Month! Thank you for bringing joy to our lab! Can't wait to see you again soon!

