

DAY OF LEARNING

10TH ANNIVERSARY

3.30.2023 | NEW YORK, NY

























Mount Seaver Autism Sinai Center for Research and Treatment





Yale SCHOOL OF MEDICINE



Advancing research through the gift of brain donation

Autism BrainNet promotes rigorous research on postmortem brain tissue to better understand the biological causes of autism and related neurodevelopmental conditions. For the latest information about the program and research findings, visit autismbrainnet.org and subscribe to our newsletter at autismbrainnet.org/newsletter.

autismbrainnet.org



The Autism Biomarkers Consortium for Clinical Trials (ABC-CT) is a multicenter research study, with the goal of developing reliable and objective measurements of social function and communication in people with autism.

medicine.yale.edu/ycci/programsprojects/autism/ chla.org/kinddlab



Autism Navigator is a free, online resource that provides educational opportunities and an interactive video to give parents and caregivers the tools necessary to provide their child the best life possible, especially low-income families who lack access to leading professionals. Extensive resources are available, from dedicated guides on topics like communication development in infants and toddlers and classroom success for children with ASDs to videos on how to administer interventions.

To learn more visit: **autismnavigator.com**



Scientific discoveries that help families with ASD are only possible through the participation of families in research studies. ASF knows many people want to participate, but don't know where to start.

ASF has created a searchable website directory to help you find a study that is right for you. Families, caregivers, service providers, and autistic adults can use the directory by searching by age, the topic of interest, or geographical location.

Some of these studies will provide financial incentives, others will provide services like support or interventions and others will share the overall results with you or provide documentation that can help you understand yourself or your family members.

autismsciencefoundation.org/participate-in-research/



Baby Navigator is an online resource that supports parents to learn about early signs of developmental concerns during infancy, and also builds skills to improve communication, social interaction and other skill development. Learn how early signs of language delay and autism can impact your child's development, what you can do about it, and how you can build your care team.

For more information visit: **babynavigator.com**



The Baby Siblings Research Consortium (BSRC) is a multidisciplinary, collaborative community of researchers and clinicians committed to understanding the developmental origins and earliest signs of autism spectrum disorder (ASD) by studying infants at a high risk of receiving an autism diagnosis. Over the last decade, through rigorous studies conducted by investigators across multiple sites, the BSRC has identified both behavioral and biological markers of risk and disrupted development prior to the age of diagnosis, sparking studies of early intervention in infancy. The BSRC shares this knowledge with investigators, parents, and clinicians who provide care to communities, and shares research strategies with all those investigating high risk populations.

For more information visit:

<u>babysiblingsresearchconsortium.org</u>



The Carolina Autism and Neurodevelopment Research Center is enrolling families across South Carolina to participate in autism research. Current study opportunities provide free autism evaluations, parenting support, and monitoring infant siblings.

sc.edu/study/colleges_schools/artsandsciences/centers_ and_institutes/uofscand/index.php



This study aims to understand how children diagnosed with autism spectrum disorder (ASD) and attention-deficit/hyperactivity disorder (ADHD) control their behavior and choose their actions. It involves completing assessment measures and computer-based games. Children diagnosed with ASD and/or ADHD who are 6–12 years old are eligible to participate in this study.

<u>rwjbh.org/childrens-specialized-hospital/</u> <u>research/cognition-research/</u>



Center for Autism Research

The goal of this study is to understand how to improve quality of life measures for autistic children who are minimally verbal or have an intellectual disability. This study is for parents of autistic children (ages 5–17) who are minimally verbal or have intellectual disability. The study involves filling out surveys online, which takes ~30 minutes.

redcap.link/pablid



Canvas Dx is the first FDA-authorized tool that helps your doctor to diagnose or rule out Autism Spectrum Disorder (ASD) in children between the ages of 18 and 72 months at risk of developmental delay

canvasdx.com



CureSHANK has a singular purpose: To accelerate the development of treatments for Phelan-McDermid syndrome and SHANK-related disorders. Our approach is to identify and fund projects that overcome critical barriers to successful drug development and to coordinate scientific efforts to improve efficiency and speed in the field.

CureSHANK.org



The IBIS Network is a group of researchers with 5 locations across the United States investigating brain development in developmental disabilities. The IBIS Network has a history of investigating brain and behavior development of infants with an older sibling with autism through use of MRI and thorough developmental assessments.

ibis-network.com





Difficulties with communication and social interaction are common issues for those with autism spectrum disorder (ASD).

If these are issues for you or a loved one, please consider participating in the IRIS research study.

In the IRIS research study, we are looking to find out whether an investigational drug might improve the symptoms of ASD that often make social interaction challenging.

To qualify, participants must:

- be 12 to 45 years of age
- have a diagnosis of autism spectrum disorder (ASD)
- have a relative, housemate, friend, or other study partner to assist during the study and attend clinic visits

There are additional requirements for participation.

The study staff will explain the complete list of requirements.

For more information, including study site locations and contact information, please visit:

clinicaltrials.gov/ct2/show/NCT05081245



RARE-X is a research program and data collection platform of the non-profit Global Genes. This research program enables rare disease patients to gather structured research-grade data, to share and interconnect their data, to accelerate rare disease diagnosis, disease understanding, and future medicines development.

RARE-X Research Program currently supports disease communities with their data collection and has developed a novel consent and data governance structure, enabling participants to agree to share their data for research.

rare-x.org



Guidebook for Participant-Friendly Clinical Trials in Autism

The Autism community is highly diverse and faces unique barriers to healthcare. These factors, combined with the rigid design of clinical research, mean that trials are often neither inclusive nor autistic-friendly. The guidance in the Guidebook aims to change this with considerations ranging from broader actions, such as involving the autism community in trial design, to more specific measures.

tinyurl.com/AutismTrialsGuidebook



Seaver Autism Center for Research and Treatment

The Seaver Autism Center at Mount Sinai is recruiting children, adolescents, and adults for a variety of research studies including genetics and rare diseases (i.e. Phelan-McDermid syndrome, DDX3X syndrome, FOXP1 syndrome, ADNP syndrome) sensory processing, biomarker discovery, measure development and clinical trials.

icahn.mssm.edu/research/seaver/research/clinical



SPARK is an online research study with a simple mission: speed up research and advance the understanding of autism.

Any individual with a professional diagnosis of autism and living in the United States can join by visiting

sparkforautism.org



Our team has been funded by the National Institutes of Health for five years to study sex differences in the development of children with and without a diagnosis of autism spectrum disorder (ASD) ages 4 to 8 years. We are particularly interested in studying the development of social behaviors, what attracts the attention of girls and boys, and the development of gender identity. For this study, we are recruiting both children with and without a diagnosis of autism to take part. This research study uses behavioral assessments, caregiver reports, and eye tracking. We are particularly interested in the development of gender identity in autistic children

med.unc.edu/healthsciences/harroplab/research/

Yale school of medicine

We are currently recruiting infants for a study on emotional development in early childhood. This study will help us develop better methods for early diagnosis and intervention for behavioral and emotional challenges.

In particular, we are recruiting infants 4 months of age or younger who have older siblings with ASD or typically developing older siblings.

Participation will include follow-up visits with your infant through 30 months of age. Visits may include assessment of social, adaptive, cognitive, and language development; studies of attention involving watching videos and listening to sounds; and play-based activities to assess your child's emotional development.

All study visits will occur at our clinic at 300 George St., Suite 900, New Haven, CT. We provide free and convenient parking. There is no cost to participate, and participants receive up to \$250.

If you are interested in participating, please fill out our inquiry form or give us a call at (203) 764-5933.

medicine.yale.edu/lab/chawarska/participate/newborns/