

Currently enrolling online/telehealth studies:

Age	Study Title and Description	Study Involvement	Clinical Diagnosis
ALL AGES	<p><u>SPARK: Simons Foundation Powering Autism Research and Knowledge</u> The SPARK study will recruit 50,000 individuals with Autism Spectrum Disorder (ASD), and their family members, from across the U.S. to join an online registry. DNA will be collected through saliva samples. The purpose of this national registry is to identify causes of ASD.</p> <p>To participate, visit sparkforautism.org/ucd</p>	<input checked="" type="checkbox"/> Online study <input checked="" type="checkbox"/> Saliva Samples <input checked="" type="checkbox"/> Questionnaires # Visits: 0	Autism Spectrum Disorder
6-36 months	<p><u>(SCREEN) Online Screening for Autism in the Community</u> The goal of this project is to test new methods of screening for ASD using an online system. Parents will complete brief screening questionnaires online when their child is 6, 9, 12, 18, 24, & 36 months old. Any children whose screening indicates developmental concerns will be invited for visits to the MIND Institute for comprehensive assessment at no cost when their child is 24 & 36 months.</p>	<input checked="" type="checkbox"/> Online study <input checked="" type="checkbox"/> Questionnaires # Visits: optional	Typical Development
6-12 months	<p><u>(TEDI) The Telehealth Evaluation of Development for Infants</u> The goal of this project is to develop and test a telehealth method for conducting behavioral assessments of infants' early social communication and development.</p>	<input checked="" type="checkbox"/> Telehealth – online study <input checked="" type="checkbox"/> Assessments # Visits: 0	Showing signs of social and communication delay
12 months to 17 years	<p><u>(Kids First) Kids First Initiative by the Hartwell Foundation</u> This study is an <i>online</i> study that will require families to enroll in a database and complete questionnaires regarding demographic and behavioral information. The goal of the study is to collect information about each child to create better classifications for Autism Spectrum Disorder.</p>	<input checked="" type="checkbox"/> Online <input checked="" type="checkbox"/> Questionnaires # Visits: 0	Autism Spectrum Disorder
MALES 3 to 7 years	<p><u>(FMRP) Family Relationships and Parenting of Children with FXS</u> The goal of this research is to examine how family relationships and the broader family environment influence developmental outcomes for young children with FXS.</p>	<input checked="" type="checkbox"/> Telehealth – online study # Visits: 0	Fragile X Syndrome or Fragile X Premutation
6 to 11 years	<p><u>(TELE) Technology-Assisted Examination of the Language Environment</u> The goal of this research study is to better understand the child's home language environment by investigating child and family characteristics that can contribute to the development of spoken language in children with FXS.</p>	<input checked="" type="checkbox"/> Telehealth -online study <input checked="" type="checkbox"/> Assessments # Visits: 0	Fragile X Syndrome or Fragile X premutation carrier
6 to 23 years	<p><u>(TOM-ASD) Telehealth Outcome Measures for Diverse Samples of Individuals with Autism Spectrum Disorder</u> The goal of the study is to train parents to administer a spoken language test to their sons/daughters in their homes. We hope to use the test in future treatment studies that will reduce the burden of travel on families, allowing them to receive therapies at home <i>*Enrolling families with a Primary language of English or Spanish</i></p>	<input checked="" type="checkbox"/> Telehealth -online study <input checked="" type="checkbox"/> Assessments # Visits: 0	Autism Spectrum Disorder

Studies temporarily not recruiting due to COVID-19– check back for updates:

Age	Study Title and Description	Study Involvement	Clinical Diagnosis
ALL AGES	<u>(BB) National Fragile X Foundation (NFXF) Collaborative BioMarker Research</u> The purpose of this study is to improve clinical care for individuals with FX-associated disorders through a biobank.	<input checked="" type="checkbox"/> Biobank <input checked="" type="checkbox"/> Blood Draw # Visits: 1	Fragile X Syndrome
2 to 3 ½ years	<u>(BRAIN) Brain Research in Autism- Investigating Neurophenotypes</u> This study examines different patterns of brain development in ASD, specifically focused on evaluating brain size.	<input checked="" type="checkbox"/> Blood Draws <input checked="" type="checkbox"/> MRI <input checked="" type="checkbox"/> Assessments # Visits: 4	Autism Spectrum Disorder or Typical Development
2½ to 7 years	<u>(PLAY-DS) Early Childhood Communication Outcome Measures for Down syndrome</u> The goal of this research study is to learn more about how samples of early communication and spoken language skills can be used to measure change over time in individuals with Down syndrome.	<input checked="" type="checkbox"/> Assessments # Visits: 1-2	Down syndrome
3 to 17 years	<u>(MMID) Memory Measures for Intellectual Disabilities</u> The goal of this study is to develop a comprehensive, computerized memory assessment for use in populations with intellectual disabilities.	<input checked="" type="checkbox"/> Assessments # Visits: 3	Typical Development, Fragile X Syndrome, or Down Syndrome
6 to 18 years	<u>(DS+ADHD) Evaluating Assessment and Medication Treatment of ADHD in Children with Down Syndrome</u> The purpose of this research study is to identify behavioral, cognitive, academic, and functional impairments that differentiate children with DS and ADHD from children with DS-only. These findings will help us to gain a better understanding of how ADHD affects children with DS.	<input checked="" type="checkbox"/> Assessments <input checked="" type="checkbox"/> Medication <input checked="" type="checkbox"/> Blood Draws # Visits: 3	Down syndrome and ADHD
6 to 25 years	<u>(MET) A Double-Blind, Placebo-Controlled Trial of Metformin in Individuals with Fragile X Syndrome</u> The goal of this 4-month placebo-controlled trial of metformin, a common type 2 diabetes medication, is to examine whether it is beneficial for improving language, cognition, and behavior in children and adults with FXS.	<input checked="" type="checkbox"/> Assessments <input checked="" type="checkbox"/> Medication <input checked="" type="checkbox"/> Blood Draws # Visits: 3	Fragile X Syndrome
6 to 25 years	<u>(TOOLBOX) A Cognitive Test Battery for Intellectual Disabilities</u> The purpose of the study is to explore whether certain types of intellectual or cognitive tests are reliable, valid, and sensitive to improvement in evaluating treatment responses among individuals with intellectual disability.	<input checked="" type="checkbox"/> Assessments # Visits: 2-3	Fragile X Syndrome, Down syndrome, or Intellectual Disability
8 to 12 years	<u>(VRAM) Virtual Reality Attention Management</u> The goal of this study is to identify and pilot key tasks and operational design for distractor resistance training, in a virtual reality (VR) classroom, with participants who have attention problems and/or ADHD with significant inattention. This study is a preliminary assessment of VR training feasibility and intervention outcomes.	<input checked="" type="checkbox"/> Assessments <input checked="" type="checkbox"/> Questionnaires # Visits: 3-4 4-6 weeks at home w/ headset	ADHD
8 to 14 years	<u>(STAAR) Specifying and Treating Anxiety in Autism Research</u> The goal of STAAR is to better characterize anxiety in ASD and evaluate if medication or Cognitive Behavioral Therapy (CBT) is more effective for children with ASD and anxiety. Participants will be offered medication, CBT, or pill placebo. If put into pill placebo, participants will be offered their choice of complimentary CBT or study medication after completion of the study.	<input checked="" type="checkbox"/> Blood Draws <input checked="" type="checkbox"/> MRI <input checked="" type="checkbox"/> Assessments # Visits: 1x per week for 16 weeks	Autism Spectrum Disorder with a clinical diagnosis of anxiety or symptoms of anxiety

(Continued) Studies temporarily not recruiting due to COVID-19– check back for updates:

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16 to 23 years	<u>(FXLA 2.0) Language Development in Fragile X Syndrome</u> The goal of the study is to learn more about how certain abilities, experiences, and biological aspects affect language abilities in individuals with fragile X syndrome and their transition into adulthood.	<input checked="" type="checkbox"/> Blood Draw <input checked="" type="checkbox"/> Assessments # Visits: 2 visits to MIND, 2 home visits	Fragile X Syndrome
12 to 15 years	<u>(COCOA) Cognitive Control in Autism</u> The purpose of the study is to gain a better understanding of cognitive functioning of individuals with Autism Spectrum Disorder (ASD) during the transition from adolescence to adulthood.	<input checked="" type="checkbox"/> MRI <input checked="" type="checkbox"/> Assessments <input checked="" type="checkbox"/> Questionnaires # Visits: 3	Autism Spectrum Disorder or Typical Development
18 to 27 years	<u>(COCOA) Cognitive Control in Autism</u> The purpose of the study is to gain a better understanding of cognitive functioning of individuals with Autism Spectrum Disorder (ASD) during the transition from adolescence to adulthood.	<input checked="" type="checkbox"/> Assessments <input checked="" type="checkbox"/> Questionnaires # Visits: 2	<i>African American or multiracial with African heritage with a diagnosis of Autism Spectrum Disorder, or Typical Development</i>
18 to 30 years	<u>(MINT) Mapping Impulsivity Neurodevelopmental Trajectories</u> The purpose of the MINT Study is to better understand how self-control develops in young adults with and without ADHD.	<input checked="" type="checkbox"/> MRI <input checked="" type="checkbox"/> Assessments # Visits: 10-12	ADHD or Typical Development
18 years or older	<u>(MARBLES) Markers of Autism Risk in Babies-Learning Early Signs</u> This study enrolls pregnant women or those likely to become pregnant soon who have a child diagnosed with ASD. The purpose of this study is to learn about risk factors occurring during pregnancy that may be associated with ASD. The babies will be followed for 3 years.	<input checked="" type="checkbox"/> Blood Draws <input checked="" type="checkbox"/> Assessments # Visits: 4 home visits, 2-4 visits to the MIND	Women who have given birth to a child with ASD <u>and</u> are currently pregnant or likely to become pregnant soon