CENTER FOR
Autism Spectrum
Disorders
www.childrensnational.org/CASD

Children's National.

CASD CHAT E-Newsletter

Autism & Genetics

Dear CASD friends and family,

This month's CASD Chat we are speaking with Ms. Hallie Andrew, MS CGC. Ms. Andrew is a genetic counselor at the Rare Disease Institute and Center for Genetic Medicine Research at Children's National. She joins us to discuss the topic of genetic testing for autistic individuals. We are constantly learning more about the role of genetics in autism, and, following an autism diagnosis, many families have questions about genetic testing. We have asked Ms. Andrew to help us answer some of the most common questions we hear about genetic testing.

Is there a genetic test for autism?

Many patients and families in the autistic community are already aware that the diagnosis of autism spectrum disorder (ASD) is made after a detailed evaluation with neurodevelopmental specialists. Genetic testing cannot diagnose someone with autism, but it could help a family understand how or why someone has autism.

For about 10%-20% of people with ASD, an underlying genetic cause can be found.

But the word "genetic" can mean a lot of different things! Sometimes autism can be from a large genetic change, like missing piece of a chromosome. Sometimes it can be a very small change, like a single letter difference in the DNA.

Why would I want genetic testing for my child with autism?

Finding a genetic cause for autism can help the healthcare team make better and more specific recommendations for that particular patient. We want all of our patients to have the support and services that are best for them as individuals so they can meet their greatest potential.

Even if a genetic diagnosis doesn't change the patient's medical management, many patients and families have reported benefit from simply having a name for something and better overall understanding.

Will genetic testing change treatment recommendations?

Sometimes, a genetic diagnosis helps us know if there could be other health problems that haven't presented yet (i.e., heart conditions, hearing loss, seizures, and others). Screening for these issues through bloodwork and imaging may be added to the patient's protocol.

Most of the time, the genetic diagnosis does not reveal any new health concerns but does help providers know what treatment for existing concerns would be best for that particular patient. If we find a genetic cause for autism, we can look to other patients with the same genetic diagnosis and ask, "What worked best for them?" For example, some genetic conditions related to autism have greater challenges with speech and communication, so those patients would need increased speech therapy or communication devices. Others may have greater challenges with motor skills, so those patients might need more physical therapy or supportive devices. In very rare cases there may even be treatment such as medications that can help improve symptoms or behaviors.

If I am interested, how do I get my child tested?

The best place to start is a baseline evaluation with your local geneticist. Your pediatrician, primary care doctor, neurologist, or other healthcare provider can give you a referral to your local genetics doctor and genetic counselor. This initial visit usually lasts about 60-90 minutes and the team will discuss which genetic test they think is best to start with.

Many genetics providers now offer telemedicine visits or specialized environments that decrease sensory overload specifically for patients with autism.

What if the genetic testing shows no abnormalities? Does that mean my child's autism is not associated with a genetic change? Does it mean my child does not have autism?

Surprisingly, the majority of patients with autism who undergo genetic testing have negative results (no known abnormalities). In these cases, we believe there is likely still is a genetic cause for the autism, but the tests available today just weren't able to find it. It could also be that the autism was caused by many factors working together such as genetics AND environmental factors. Negative genetic testing does not rule out a diagnosis of autism. Instead, it indicates that science and medicine simply have a lot more to learn about autism.

Genetic medicine is constantly changing and improving. It is important to check in with your genetics team at least once per year to ask if there are any updates to previous tests or if new tests have become available.

What does genetic testing involve? How should I prepare my child for the appointment?

Genetic testing should only be ordered after a thorough evaluation with a genetics doctor. The genetics team will do a physical exam and will collect information such as the pregnancy history, birth history, and developmental history. Most genetics providers will take a detailed family history. You should bring any relevant health records to your visit and be prepared to review testing that's been done so far.

Genetic testing can be performed on a either a blood sample or cheek swab (also called "buccal") sample. Most of the time, the sample will not be collected the same day as your visit, because genetic testing usually requires prior authorization by insurance companies. In some cases, the sample for genetic *testing can be collected the same day as the visit. After meeting with the geneticist and genetic counselor, the healthcare team will discuss different options for testing and insurance coverage for these tests. If insurance does not cover genetic testing, there might be other options through self-pay or research testing.*

How could my child have a genetic disorder, if no one else in their family has autism?

A lot of people believe the word "genetic" means it must be inherited or passed down from the parents, but this is not always true. Sometimes a genetic cause for autism runs in families, but many times it can be something new that happened in a child for the first time.

As a brief genetics review: humans have about 20,000 different genes. We usually have two copies of each gene, as they come in pairs: one from our biological mother, one from our biological father.

For recessive conditions, parents are usually carriers, which means they have one copy of the gene that is working, and one copy that is not working. If two people are carriers for the same recessive condition, there is a 25% chance with each pregnancy that both parents pass down their non-working copy of the gene, and that child with both non-working copies of the gene is affected. That means there's a 75% for the same couple to have children who are unaffected, as long as they get one working copy of the gene.

For dominant conditions, only one copy of the gene needs to be non-working to be affected. Many cases of neurodevelopmental conditions such as autism occur due to a random mutation (or "spelling mistake") that neither parent was a carrier for but happened as a new event in the child for the first time, right after the sperm and the egg came together. This is still considered a "genetic" disorder, even though it was not inherited.

Profiles Celebrating Neurodiversity

This month we highlight Jordyn Zimmerman. Jordyn recently received her bachelor degree from Ohio University and is completing graduate course work at Boston College. However, getting to these advanced achievements was not a straightforward course. Jordyn struggled with communication throughout most of her school career. Frustration led to challenging behaviors, making school into a nightmare. Jordyn attended specialized schools through much of high school. When she returned to public school at the age of 17, she was on track to earn a modified diploma with a focus on developing basic work skills. However, all of this changed for her, once she started using an iPad-based AAC to communicate. Through technology, Jordyn has been able to communicate fully, advocating for herself and others. In addition to completing high school and college, Jordyn writes for blogs and publication and presents nationally. She was the subject of a recent documentary *This is Not About Me.*

2021 Calendar of Events

Free Parent Support Group

Where: Virtual
When: every Monday at 1 PM EST
Dr. Dan Shapiro, friend of CASD, will be offering a free parent support group, every Monday at 1 PM EST. To register, click here.

ADHD In Children and Adolescents: Medication Workshops for Parents

Where: Virtual
When: Thursday evenings in January, 8-9 EST
Dr. Dan Shapiro, friend of CASD, will be offering a live discussion on Zoom about topics including: how and why to do a medication trial, managing medication side effects, and uneven medication coverage and discontinuation trials. To register, click here.

Teaching Collaborative Problem Solving to Children & Adolescents

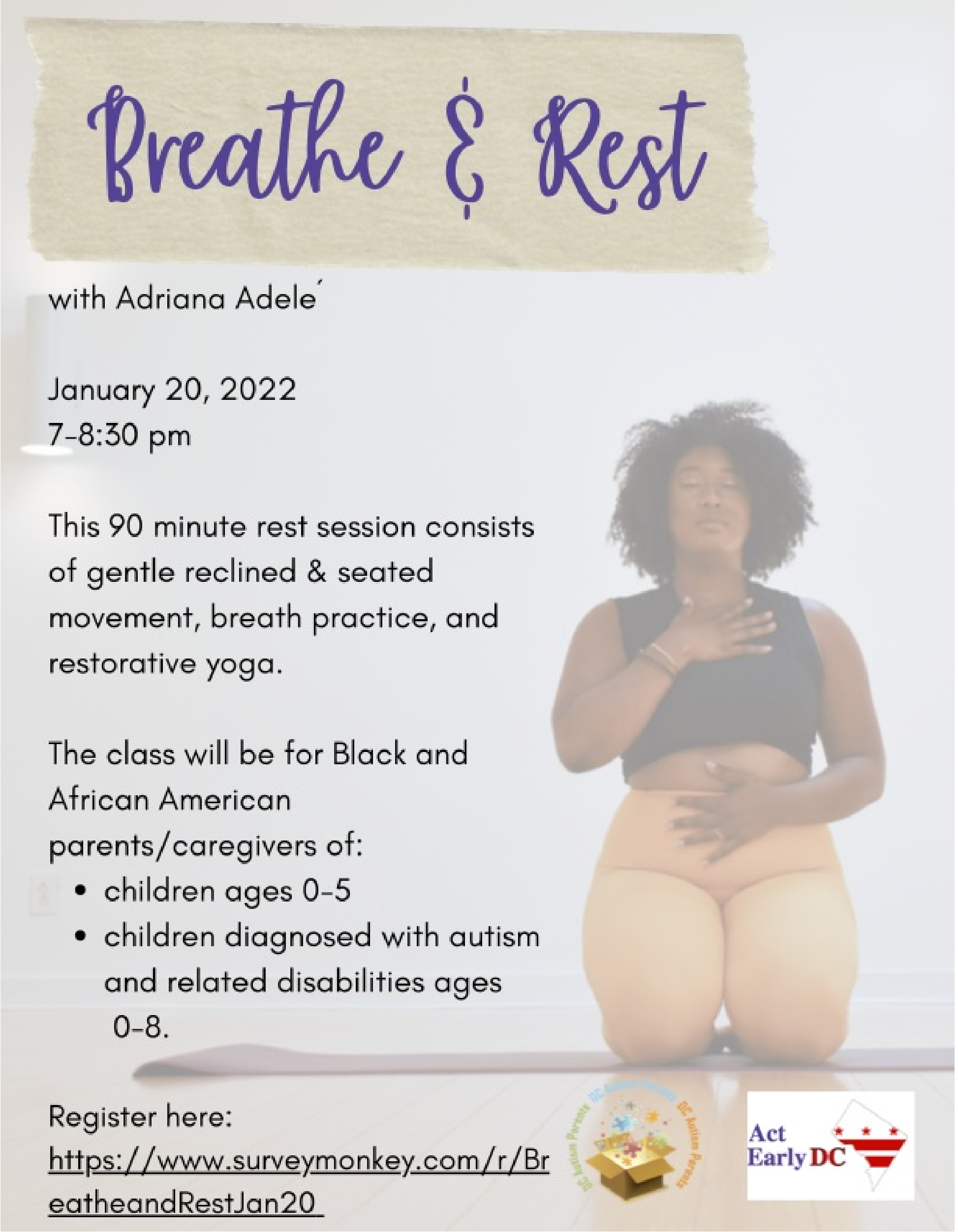
Where: Virtual
When: Three Tuesdays in January, 7:30-8:30 AM EST
Dr. Dan Shapiro, friend of CASD, will be offering a live discussion on Zoom about topics including: the case for collaborative problem solving, how to do collaborative problem solving, and a family systems approach to collaborative problem solving. To register, click here.

This 90 minute rest session consists of gentle reclined & seated movement, breath practice, and restorative yoga.

The class will be for Black and African American parents/caregivers of children ages 0-5; and parents/caregivers of children diagnosed with autism and related disabilities ages 0-8.

Sign up here:
https://www.s

urveymonkey.com/r/BreatheandRestJan20



Breathe & Rest

with Adriana Adelé

January 20, 2022
7-8:30 pm

This 90 minute rest session consists of gentle reclined & seated movement, breath practice, and restorative yoga.

The class will be for Black and African American parents/caregivers of:

- children ages 0-5
- children diagnosed with autism and related disabilities ages 0-8.

Register here:
https://www.surveymonkey.com/r/BreatheandRestJan20

Anxiety in Children & Adolescents: One night Workshop for Parents
Where: Virtual
When: January, 27th, 8-9:30pm
Dr. Dan Shapiro, friend of CASD, will be offering a one night workshop for parents/caregivers on Zoom about topics including:how to recognize in children and family systems, how to do child-centered exposure therapy, and how to do patient-centered accommodation reduction. To register, click here.

Pathfinders for Autism provides a list of programs for all ages including:

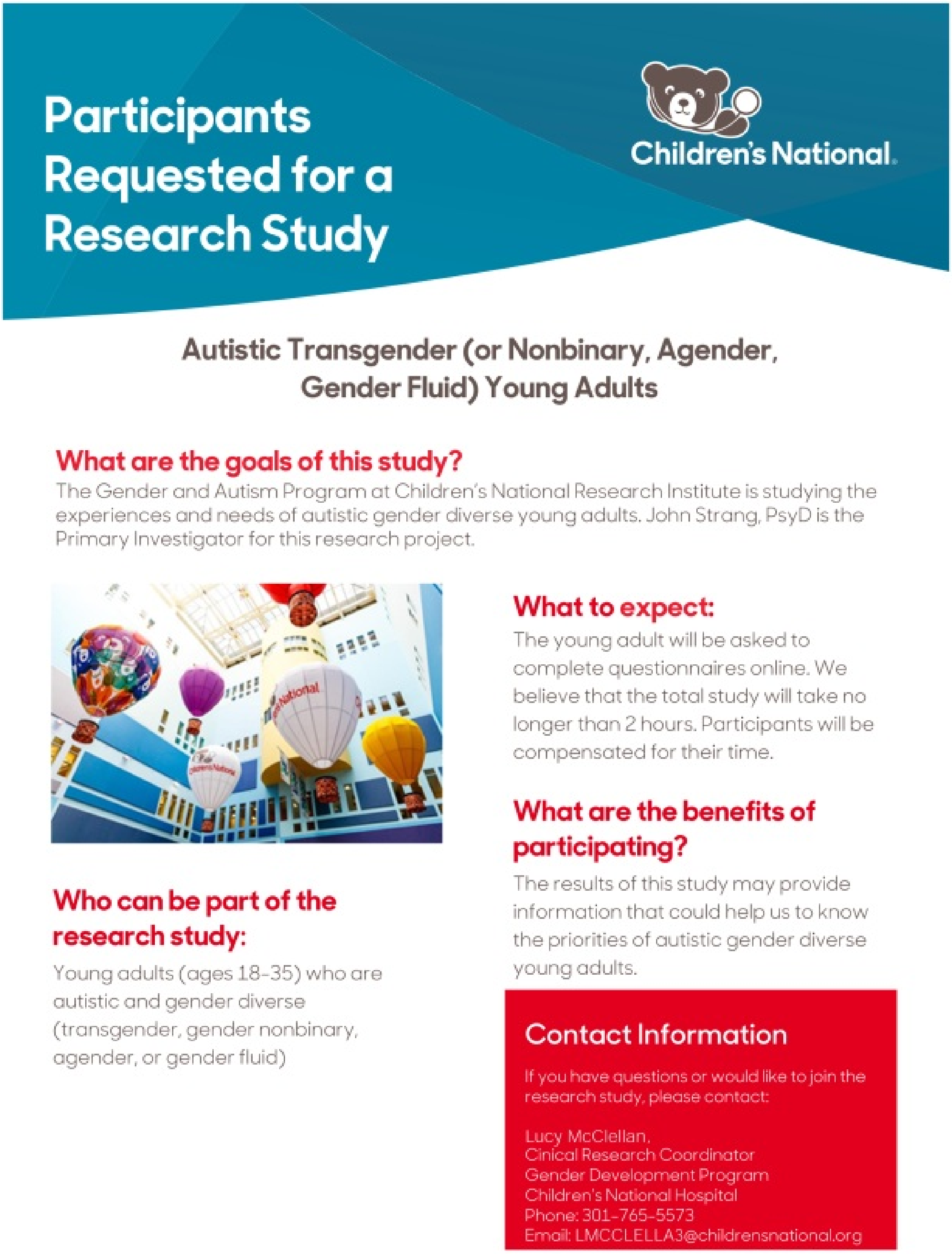
- Online group for spouses/partners of adults with Asperger's;
- Information on transitioning services and Job skills;
- Online program for parents of picky eaters
- Pediatric feeding disorders in autism

The 20th Annual Autism Conference (#CARDAAC)! The Center for Autism and Related Disorders (CARD) will host a dynamic virtual event featuring real-time sessions delivered by experts working in the autism spectrum disorder (ASD) field.

The *Unstuck* author team has created short videos to help parents of children with executive functioning difficulties. Please click the playlists below to view the videos in both English and Spanish!

If you like the videos and your child attends school in Virginia, ask your school about being involved in our *Unstuck* implementation project. You can learn more about the project here: https://lp.constantcontactpages.com/cu/nE4K95z/UOTelementaryschool

Playlists of all videos



Participants Requested for a Research Study

Children's National

Autistic Transgender (or Nonbinary, Agender, Gender Fluid) Young Adults

What are the goals of this study?

The Gender and Autism Program at Children's National Research Institute is studying the experiences and needs of autistic gender diverse young adults. John Strang, PsyD is the Primary Investigator for this research project.

What to expect:

The young adult will be asked to complete questionnaires online. We believe that the total study will take no longer than 2 hours. Participants will be compensated for their time.

What are the benefits of participating?

The results of this study may provide information that could help us to know the priorities of autistic gender diverse young adults.

Who can be part of the research study:

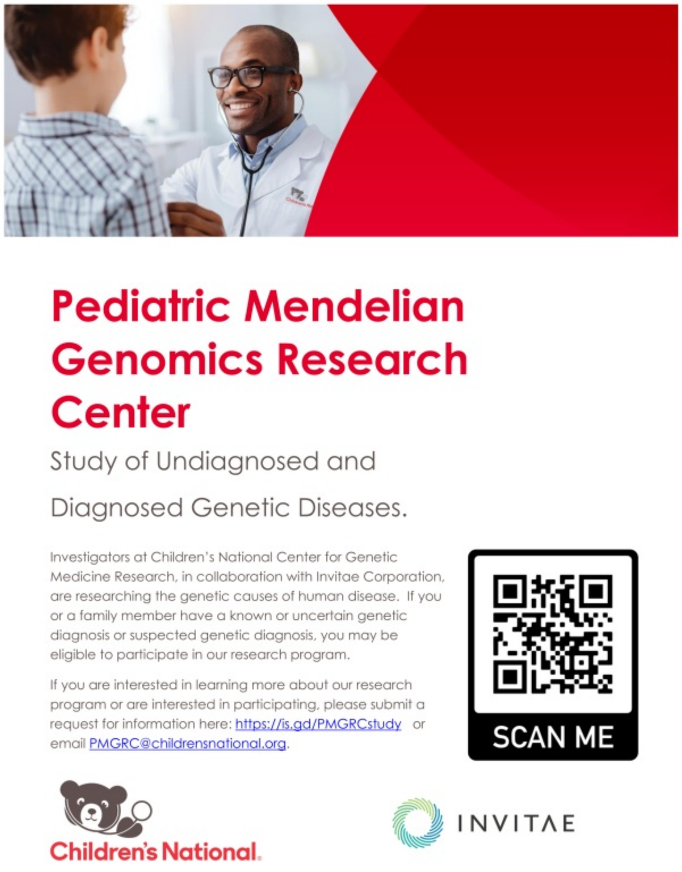
Young adults (ages 18-35) who are autistic and gender diverse (transgender, gender nonbinary, agender, or gender fluid)

Contact Information

If you have questions or would like to join the research study, please contact:

Lucy McClellan,
Cinical Research Coordinator
Gender Development Program
Children's National Hospital
Phone: 301-765-5573
Email: LMCCLELLA3@childrensnational.org

Investigators at Children's National Center for Genetic Medicine Research, in collaboration with Invitae Corporation, are researching the genetic causes of human disease. If you or a family member have a known or uncertain genetic diagnosis or suspected genetic diagnosis, you may be eligible to participate in our research program. Please see the flyer to the left to learn more.



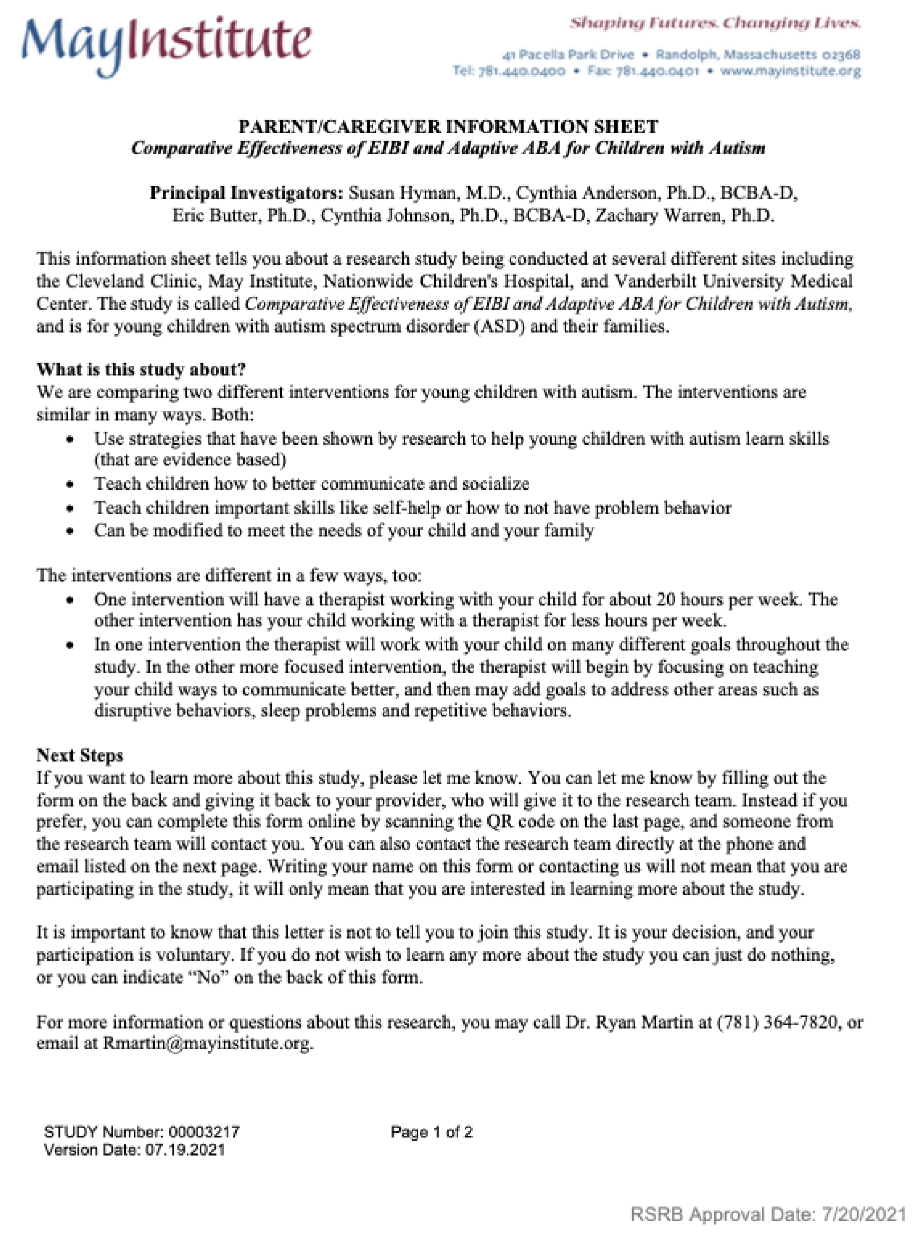
Pediatric Mendelian Genomics Research Center

Study of Undiagnosed and Diagnosed Genetic Diseases.

Investigators at Children's National Center for Genetic Medicine Research, in collaboration with Invitae Corporation, are researching the genetic causes of human disease. If you or a family member have a known or uncertain genetic diagnosis or suspected genetic diagnosis, you may be eligible to participate in our research program.

If you are interested in learning more about our research program or are interested in participating, please submit a request for information here: https://is.gd/PMGRCstudy or email PMGRC@childrensnational.org.

Hover over this QR code to complete an interest form for this study.



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PARENT/CAREGIVER INFORMATION SHEET
Comparative Effectiveness of EIBI and Adaptive ABA for Children with Autism

Principal Investigators: Susan Hyman, M.D., Cynthia Anderson, Ph.D., BCBA-D,
Eric Butter, Ph.D., Cynthia Johnson, Ph.D., BCBA-D, Zachary Warren, Ph.D.

This information sheet tells you about a research study being conducted at several different sites including the Cleveland Clinic, May Institute, Nationwide Children's Hospital, and Vanderbilt University Medical Center. The study is called *Comparative Effectiveness of EIBI and Adaptive ABA for Children with Autism,* and is for young children with autism spectrum disorder (ASD) and their families.

What is this study about?
We are comparing two different interventions for young children with autism. The interventions are similar in many ways. Both:

- Use strategies that have been shown by research to help young children with autism learn skills (that are evidence based)
- Teach children how to better communicate and socialize
- Teach children important skills like self-help or how to not have problem behavior
- Can be modified to meet the needs of your child and your family

The interventions are different in a few ways, too:

- One intervention will have a therapist working with your child for about 20 hours per week. The other intervention has your child working with a therapist for less hours per week.
- In one intervention the therapist will work with your child on many different goals throughout the study. In the other more focused intervention, the therapist will begin by focusing on teaching your child ways to communicate better, and then may add goals to address other areas such as disruptive behaviors, sleep problems and repetitive behaviors.

Next Steps
If you want to learn more about this study, please let me know. You can let me know by filling out the form on the back and giving it back to your provider, who will give it to the research team. Instead if you prefer, you can complete this form online by scanning the QR code on the last page, and someone from the research team will contact you. You can also contact the research team directly at the phone and email listed on the next page. Writing your name on this form or contacting us will not mean that you are participating in the study, it will only mean that you are interested in learning more about the study.

It is important to know that this letter is not to tell you to join this study. It is your decision, and your participation is voluntary. If you do not wish to learn any more about the study you can just do nothing, or you can indicate "No" on the back of this form.

For more information or questions about this research, you may call Dr. Ryan Martin at (781) 364-7820, or email at Rmartin@mayinstitute.org.

STUDY Number: 00003217
Version Date: 07.19.2021

Page 1 of 2

RSRB Approval Date: 7/20/2021

20+ free resources available to view anytime, anywhere!

Enjoy these information-packed free webinars on your own or make them a powerful group learning event with your colleagues, friends, and family members. Topics include:

- Working/learning in groups
- Face-to-face communication
- Social anxiety
- Executive functions
- Children's stress
- Self-regulation
- Individual webinars on 10 core Social Thinking Vocabulary

Hosted by Social Thinking.

Community Resources & Events

The Drexel Autism Institute is seeking youth **ages 13-29 on**

Advocacy Resources
Autistic Self Advocacy Network-

the autism spectrum who are transitioning to adulthood. They are also looking for these youths' **caregivers and providers** to participate in a study about **Team Trestle, an application for transition planning and coordination.** This virtual tool is designed to help autistic individuals meet their life goals by engaging autistic youth/young adults, their parents/legal guardians, and providers in the collaborative process of **implementing and achieving goals during the transition to adulthood**. For more information, check out the flyer. If you're interested, fill out the Interest Form at https://tinyurl.com/TrestleInterest [tinyurl.com] or email our team at sodi@drexel.edu.

The Autism Institute at Drexel University is seeking parents/caregivers OR preschool/daycare providers of autistic children aged 24-60 months who have trouble speaking and use a communication tool (i.e., PECS, AAC device). We want **to better understand the use of communication tools** and how collaboration occurs about communication tool use in home/school settings **for minimally verbal preschool students with autism.** During a 90-minute focus group or interview we want to learn how teams work together to support children who use communication tools. If you are interested, please fill out the Interest Form at https://tinyurl.com/EPICfocus [tinyurl.com] or email sodi@drexel.edu and we will contact you.

Navigating College: A Handbook on Self Advocacy

Resources on Anti-Racism

Spectrum Support's Social Stories on Racism
ASAN's What is Police Violence?: A Plain Language Booklet
@TheMorganCruise Worksheets for Black Children

COVID-19 Safety Resources

Behavioral Directions LLC's Safety Teaching Protocol

COVID-19 National and Local Government Resources

Centers for Disease Control and Prevention
World Health Organization
DC Department of Health
Maryland Department of Health
Virginia Department of Health
U.S Department of Education's Individuals with Disabilities Education Act (IDEA) Part C Dispute Resolution Procedures
U.S Department of Education's Individuals with Disabilities Education Act (IDEA) Part B Dispute Resolution Procedures

Visit Children's National Hospital's COVID-19 Resources