CENTER FOR Autism Spectrum Disorders

www.childrensnational.org/CASD

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CASD CHAT E-Newsletter

Celebrating Black History Month

Hello Families!

February is Black History month. We are proud to be a part of the Washington, DC community, which has a rich heritage of Black communities, culture, and activism. Although cultural and racial experiences have not always been honored in autism research and practice, there is a growing amount of attention paid to how racial disparities can impact access to care and family experience.

In the past, research has suggested that Black children are often delayed in receiving a diagnosis of autism and are less likely to be diagnosed with autism than their White peers. Recent data from the CDC, however, shows that these gaps are beginning close, particularly for young children. We are also continuing to learn more about what factors influence *when* children of different races receive a diagnosis of autism. A recent study published by Dr. Serene Habayeb of the CASD research team suggested there are fewer Black children being diagnosed with autism in middle/late childhood (i.e., after age six) compared to White children. Additionally, when getting a diagnosis later in childhood, Black children showed relatively more autistic traits and lower cognitive skills, while White children showed relatively more emotional problems and higher cognitive abilities. The research also showed that older Black children, particularly those with higher IQs, less obvious autism symptoms, and more emotional problems, might be less readily recognized as having autism. These findings may indicate that Black children and their families have greater difficulty accessing a specialty autism clinic. What this suggests is that racial disparities in early identification of autism may be diminishing but disparities may persist among children diagnosed later in childhood and adolescence.

There is also an increasing push in the field of autism, led by Black psychologists, to recognize the impact of systemic discrimination and racism on access to care, and to begin addressing these barriers. A recent call to action on this topic identified that differences in how parents think and talk about autism, internalized provider biases, the lack of culturally appropriate tools, and insurance and financial barriers all work together to limit access to care for Black children and families. The authors recommended amplifying Black voices in organizations, learning about our own and others' cultural identities, and working to address systems-level barriers to care. At CASD, we are working to learn and address issues of racism and are coordinating with other systems in the hospital to make our clinic more accessible.

This CHAT was written by Drs. Serene Habayeb and Allison Ratto.

Profiles Celebrating Neurodiversity

This month, we are excited to highlight the work of Morénike Giwa Onaiwu. Ms. Onaiwu is an autistic woman, who works as a disability rights advocate and higher educator. She was late-diagnosed with autism and is also the mother to both autistic and non-autistic children. Ms. Onaiwu is currently a Humanities Scholar at Rice University, and she has served as an invited speaker, consultant, and advocate at the White House, the United Nations, and in various political advocacy and research-funded work through the National Institutes of Health and other high-profile organizations. Ms. Onaiwu has been involved in advocacy in a number of areas, including housing, HIV, and disability rights and autism. Her visibility and advocacy as a Black autistic women has highlighted the importance of neurodiversity and the ways in which disability intersects with other identities.

The Talk— Black, Autistic, and Male: One Family's Experience

We would like to share an interview with a family of a college-bound autistic young adult and an accompanying reflection by Tawara Goode, Director of the National Center for Cultural Competence and Director of the Georgetown University Center for Excellence in Developmental Disabilities.

Click here for the video

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.

Dr. Shapiro is offering new courses for parents of different age groups. To learn more about these courses, please visit his website: http://www.parentchildjourney.com/

Pathfinders for Autism (https://pathfindersforautism.org/calendar/) provides a list of programs for all ages including video group for spouses/partners of adults with Asperger's; Transitioning services and Job skills; Baby and Family Navigator programs, and new this month, Autism from the Autistic Perspective and free Pediatric Occupational Therapy Screening and more!

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

Enrollment for the study below will be ending soon. Please email Jessica Smith, jsmith9@childrensnational.org, or Laura Campos, lcampos@childrensnational.org to get involved!

Participants Needed

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Using MRI Technology to Study Executive Functioning

About this study: Georgetown University Developmental Cognitive Neuroscience Laboratory and Children's National Hospital are studying executive function skills like attention, memory, and learning using magnetic resonance imaging (MRI). Using MRI technology, we expect to pinpoint the parts of the brain that are responsible for these cognitive functions and hope to determine the potential of using MRI as a tool to help clinicians personalize treatment.

Who can be part of this research study?

Children ages 8-13 with executive functioning (EF) challenges may be eligible to participate.

What are the benefits of taking part in this research study?

The results of this study may provide information that could help improve the accuracy and efficiency of future EF treatments. In addition, we will pay you for your time, provide free parking, and give you a picture of your child's brain.

What will participants be asked to do?

If eligible, families will be invited to one visit at Georgetown University's Center for Functional and Molecular Imaging. Visits will be scheduled at a time convenient for participating families, including weekends.

During the visit, your child will receive behavioral testing and an MRI scan. While getting the scan, your child will complete computerized tasks that are first practiced outside of the scanner. Parents may be asked to participate in an interview and complete paper questionnaires over Zoom. COVID-19 precautions are being taken and are adjusted based on public health guidance.

Contact Information

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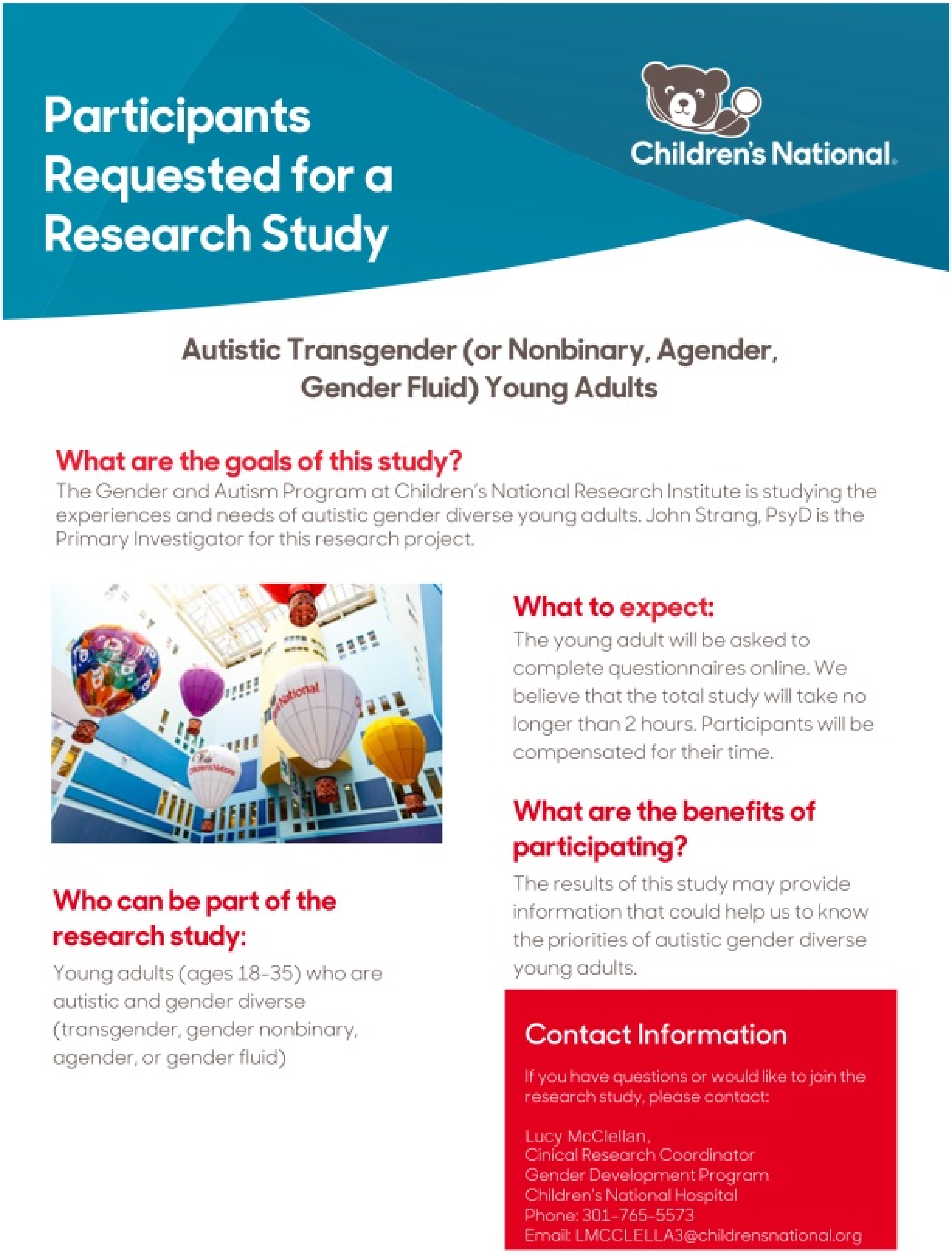

Participants Requested for a Research Study

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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:

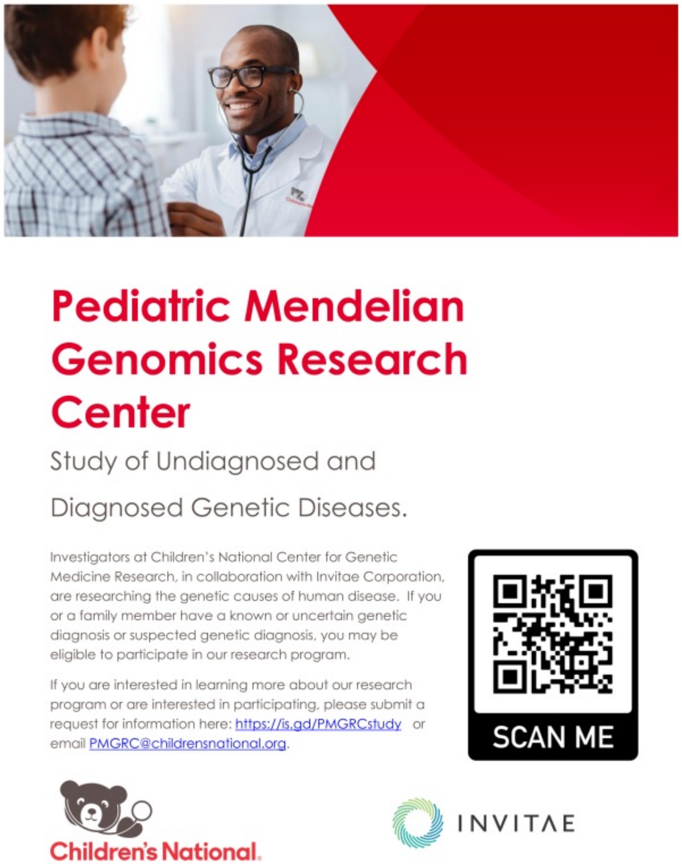
Young adults (ages 18-35) who are autistic and gender diverse (transgender, gender nonbinary, agender, or gender fluid)

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.

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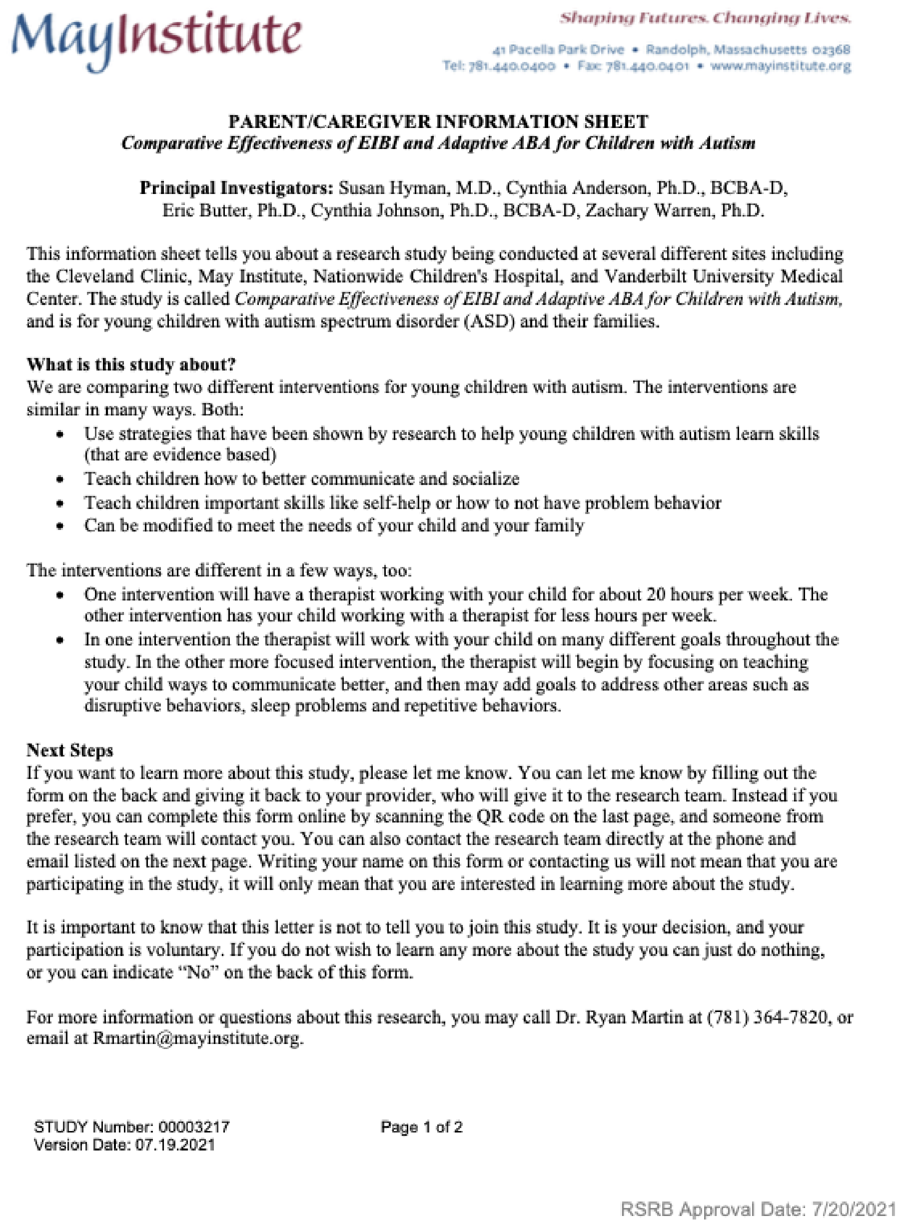
If you are interested in learning more about our research program or are interested in participating, please submit a request for information here: https://is.gd/PMGRCstudy or email PMGRC@childrensnational.org.

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

We'd like to share the below information regarding the Pivotal Response Treatment project. The pivotal project was developed by the PRT team (in collaboration with the Koegal center at the University of California-Santa Barbara) and given the usefulness of PRT resources and books, we wanted to share the information on the program.

For more information, please see this link: https://education.ucsb.edu/autism/research/prtapp

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

Advocacy Resources
Autistic Self Advocacy Network-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