Guidelines for today:

• We will be going in order of age of person with ASD or family member (one COVID related not specific to ASD at the end)
• They will all be listed on our ”Participate in Research” page
• Tell your friends!
• Questions in the question box

ahalladay@autismsciencefoundation.org
Perceptions of unusual behaviors in children

Zoe Sargent, University of Virginia
What do kids think about unusual behaviors?

- Young children understand unwritten rules for behavior
- Autism is characterized by unusual behaviors
What do kids think about unusual behaviors?

• **WHO**: Any child 4-7 years old

• **WHAT**:  
  - 6 short stories with characters behaving in different ways  
  - Ask about behaviors and characters

• **WHEN**: 15-30 minutes, scheduled Zoom meeting

• **WHY**:  
  - No direct benefits to families  
  - But, it may help us learn more about how children understand behavior
What do kids think about unusual behaviors?

• **HOW**: Contact zsargent@virginia.edu for more details or to set up a time to participate!
  - Please include child’s name, age (in years), and some times you would be available to meet
Food and Eating Behaviors

Anita Aalia Panjwani, Purdue University
Food and Eating Behaviors in Children with ASD in Response to COVID-19

Purdue Autism Research Center
Anita Panjwani, PhD
• **Purpose:** to understand how children with ASD are responding to the coronavirus (COVID-19) outbreak as it relates to food and eating behaviors. This information will help us understand how to tailor support strategies to address the dietary needs of children with ASD during high-stress periods of time.

• By participating in this study, your family will be contributing to the body of knowledge about how large-scale crises affect the food environment and dietary needs of children with ASD. There is no personal benefit guaranteed by participating in this study.

• **Eligibility:** parent of a child under 18 years of age with a diagnosed Autism Spectrum Disorder (ASD) living in the U.S.
Do you have a child with Autism Spectrum Disorder?

Researchers at Purdue University want to learn how COVID-19 has impacted your child’s food and eating behaviors.

Contribute to this nationwide study by taking an online survey!

10 participants will receive a $20 gift card as part of a raffle.

- One-time 15-20 minute anonymous online survey
- Chance to win one of ten $20 Amazon gift cards
- URL for online survey: [https://tinyurl.com/y8q572vh](https://tinyurl.com/y8q572vh)
- Find us at our Facebook page: [https://www.facebook.com/purdueautism/](https://www.facebook.com/purdueautism/)

Contacts:

Dr. Anita Panjwani
apanjwan@purdue.edu

PI: Bridgette Kelleher
bkelleher@purdue.edu
Parent preferences about technology based interventions for children and young people with autism spectrum disorders: The PATH study

Nancy Kouroupa
The PATH study

Our goal

• Explore parents’ attitudes towards use of a range of different types of technologies to support interventions for young people with ASD.
  • What is parents’ preferred technology device?
  • What are parents concerns about the use of technology for intervention with children with ASD?
  • What sources of information influence parental decisions towards technology based intervention?
The PATH study

We need
- Parents/carers of children with autism
- The child with autism (suspected/diagnosed) aged 0-18 years old
- Understanding of English

What does the study involve?
- Anonymous online questionnaire
- 10-20 minutes
- No more involvement
We are looking for parents of children with autism aged 0-18 years to participate in research.

WHAT ARE PARENT’S PREFERENCES ABOUT TECHNOLOGY BASED SUPPORT WHEN IT COMES TO CHOOSING THEIR CHILD’S SESSION?

There is limited research about the use of technology in autism research. Working together while learning about parent’s preferences we could change this!

We are researchers at the University of Hertfordshire. We would like to invite parents/carers to complete a questionnaire and share your views about using phones, tablets, virtual reality goggles and robots with children and young people on the autism spectrum. Your child doesn’t need to have used any of these technologies for you to take part in this research.

Here is the link to access a survey that lasts for about 15-20 minutes (https://herts.eu.qualtrics.com/jfe/form/SV_6s6AJo88ZoYkvch)

For more information, contact: Nancy Kouroupa - akl8adj@herts.ac.uk

University of Hertfordshire
Ethics number: LMS/PGR/UH/04164
Telehealth for anxiety

Lynn Hana and Eric Storch, Baylor College of Medicine
Parent-Led Cognitive Behavioral Teletherapy for Children with Anxiety and ASD

- FREE treatment for anxiety designed to fit the needs of children with autism spectrum disorder (ages 7-13 years old)
- Sessions delivered via video to your home
- Families will be in one of two groups; low-intensity or standard
- Compensation for assessments completed (total $120)

*Residents of Texas
Parent-Led, Stepped-Care CBT for Children with Anxiety and ASD

- FREE treatment for anxiety designed to fit the needs of children with autism spectrum disorder (ages 4-14 years old)
- Treatment will be provided in "steps" that vary by intensity beginning with Step 1
- If needed, families will “step-up” to receive a higher intensity in Step 2
- Compensation for assessments completed (total $160)

*Residents of Texas
For more information, please email anxietyandASD@bcm.edu

Study staff will schedule a brief screening over the phone to determine initial eligibility.
Service needs during COVID

Emily Ferguson, UCSB
**AN ONLINE PARENT/CAREGIVER SURVEY**

We hope to better understand the specific needs and experiences of families nationwide with autistic children (aged 2 or older), adolescents, or adults during COVID-19. If we have a better understanding of your family’s needs, we can develop better supports for the autism community.

**Brief Parent Survey: Assessing Service Needs Within the Autism Community During COVID-19**

**UCSB Koegel Autism Center**

**Who?**

Parents/primary caregivers of an individual (aged 2 or older) diagnosed with autism spectrum disorder can participate in our study by completing this brief survey.

**Why?**

Your answers will provide helpful information to autism researchers and service providers to better support you and your family during the COVID-19 crisis and its aftermath.

A comprehensive list of nationwide resources will be offered alongside the survey.

To participate and gain access to our resource page, please follow this link: [COVID-19 Experiences Survey](#).

For more information, please email us at autism@ucsb.edu
Thank you for your consideration! Sharing your family’s experience will help us develop better supports for the autism community during COVID-19 and its aftermath.

Contact us: mariajimenezmunoz@ucsb.edu for assistance in English or Spanish.

https://ucsb.co1.qualtrics.com/jfe/form/SV_06Qui2j7mDT1WqF
Adult Development and Aging in Autism

Greg Wallace, PhD

Associate Professor
Speech, Language, and Hearing Sciences
The George Washington University
https://blogs.gwu.edu/autismlab/
Aging and Autism

• The first individuals diagnosed with autism in the 1940s are only now reaching old age meaning that opportunities for studying aging in autism to date have been limited

• Thus, the knowledge base on aging in autism is woefully small

• Particularly important since we now have CDC-based estimates of autism rates among adults: ~2.2% or ~5,400,000 adults in the USA

• We want to hear about research priorities from central stakeholders, adults with autism

Mukaetova-Ladinska et al. (2012) *Int J Geriatr Psychiatry*
Participate in Research On Adult Development and Aging in Autism

Who can participate?
• Adults on the autism spectrum

What do you do?
• Complete an open-ended interview over the phone or a web-based calling system (e.g., Zoom or WebEx) and answer some basic demographic questions

How long does it take?
• 30-60 minutes, scheduled at a mutually convenient time.

Is there payment?
• No, this is not a paid study.

If interested, contact:
Colin Weiss or Alex Job Said at:
ladn@gwu.edu
Simons Searchlight
Misia Kowanda, Simons Foundation
### Genetic Changes We Study

<table>
<thead>
<tr>
<th>Chromosome Region</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1q21.1</td>
<td></td>
</tr>
<tr>
<td>2p16.3</td>
<td></td>
</tr>
<tr>
<td>2p24 duplication</td>
<td></td>
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<tr>
<td>2q37 deletion</td>
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<td>3p7</td>
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</tr>
<tr>
<td>8q23.1</td>
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<tr>
<td>9q34 duplication</td>
<td></td>
</tr>
<tr>
<td>15q11.2-q13.1</td>
<td></td>
</tr>
<tr>
<td>15q13.3 deletion</td>
<td></td>
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<td>15q24 deletion</td>
<td></td>
</tr>
<tr>
<td>16p11.2*</td>
<td></td>
</tr>
<tr>
<td>16p12.2 deletion**</td>
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</tr>
<tr>
<td>16p13.11</td>
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</table>

### The Simons Searchlight Gene List

The Simons Searchlight gene list contains 180 gene changes (orange) and 24 copy number variants (purple) that are known to be associated with autism and other neurodevelopmental disorders. Any result returned by SPARK, another SFARI initiative, are eligible in Simons Searchlight.

### What is Simons Searchlight?

Simons Searchlight is an international research registry for individuals who have a diagnosis with a genetic change associated with ASD or other neurodevelopmental conditions. The list of eligible genes is the same as SPARK, our affiliate study at the Simons Foundation Autism Research Initiative (SFARI).
Enrollment and participation

Simons Searchlight

Participation Process

**Step 1**
Register Online
Create an account for yourself. Data will be stored securely without identifiable information.

**Step 2**
Complete Consent
Consent to share your data, provide an optional research sample, and be contacted for future research studies.

**Step 3**
Add a Child with a Genetic Change
If you have a child who has the genetic change, add them and complete their consent.

**Step 4**
Submit a Lab Report
Upload your or your child’s genetic lab report. We’ll review it to make sure you’re in the right place.

**Step 5**
Complete Medical History Phone Call
Schedule your medical history phone call with our genetic counselor. During the call, you’ll be asked for a detailed medical and family history that we will track over time.

**Step 6**
Take Online Surveys
Check your dashboard for surveys. Follow us on social media for study updates and helpful information!

**Step 7**
Provide a Sample for Research Storage
If interested, your family may participate in a stored dried or saliva collection. Researchers may use these samples to learn more about the genetic change.

**Step 8**
Continue Participating
We add surveys to the study as needed, and some surveys are repeated every year, along with a follow-up medical history phone call. The study team tracks updates over time.

Simons Searchlight Community
Collect **high quality data** in a standardized way for these rare genetic conditions.

Share this **de-identified data to qualified scientists** to help move research forward on these conditions.

Contribute to **advancements** that will also help future families.
The Genes to Mental Health Network (G2MH)

Dr. Christa Martin
Associate Chief Scientific Officer, Geisinger
Professor & Director, Autism & Developmental Medicine Institute

Presenting on behalf of the G2MH Network
Genetic Causes of Developmental Brain Disorders

At least **40-45%** of individuals with a DBD referred for clinical genetic testing have an identifiable genetic diagnosis
(CNV and single gene combined)

CNV/Chromosomal

Other: unidentified genes, multiple gene interactions, environment

Single gene
(FMR1, CHD8, etc.)

(22q11.2, 16p11.2, etc.)
Genetic Causes of Developmental Brain Disorders

- Single gene
  - (FMR1, CHD8, etc.)
- CNV/Chromosomal
  - (22q11.2, 16p11.2, etc.)
- Other:
  - unidentified genes,
  - Multiple gene interactions,
  - environment

*In Autism Spectrum Disorder – the diagnostic yield is ~25% (CNV and single gene combined)*
Behavioral vs. Etiological Diagnosis

- Find a cause
- Provide information about recurrence risk
- Targeted medical monitoring
- Etiology-specific interventions
The Genes to Mental Health (G2MH) Network

- NIH-funded U01 project
- Initiated in June 2019
- International network
  - Currently includes:
    - 4 collaborative projects
    - 15 sites (11 North America; 3 Europe; 1 Africa)
Genes to Mental Health (G2MH) Network

4 Collaborative Projects
15 Sites
Funded by NIMH and NICHD
G2MH Principal and Co-Investigators

Organizing Institutes:

Geisinger
David Ledbetter
Christa Lese Martin
Christopher Chabris
Brenda Finucane
Scott Myers
Cora Taylor

Penn
Raquel Gur

Boston Children’s Hospital
David Glahn

Broad Institute
Elise Robinson
Anne O’Donnell-Luria

Cardiff
Marianne Van Den Bree
Michael Owen
Nigel Williams

Children’s Hospital of Pennsylvania
Donna McDonald-McGinn
Laura Almasy

Hospital for Sick Children, Toronto
Jacob Vorstman
Anne Bassett
Stephen Scherer

Katholieke Universiteit Leuven
Ann Swillen

Maastricht University
Therese Van Amelsvoort

Sainte-Justine University Hospital Center
Sebastien Jacquemont

UC San Diego
Jonathan Sebat

UCLA
Carrie Bearden

University of Cape Town
Kirsty Donald

University of Washington
Rachel Earl
Evan Eichler

Washington University St. Louis
John Constantino
Dustin Baldridge
Goals and Impact of Network

- Identify individuals and families with genetic causes of neurodevelopmental and psychiatric disorders, including autism.
- Characterize the symptoms associated with these genetic causes.
- Understand how family genetic background contributes to the risk for developmental and psychiatric symptoms.
- Discover early interventions to prevent symptoms.
- Develop targeted treatments.
- Identify harmful or inadequate interventions.
Recruitment

• Who is eligible?
  • Children and adults *with a known genetic cause of autism* and their family members (with and without genetic change)

• Study is focused on:
  • 1q21.1 deletions
  • 15q13.3 deletions
  • 16p11.2 deletions and duplications
  • 22q11.2 deletions and duplications
  • *CHD8* single gene changes
  • But, also interested in others …
Who to Contact for More Information?

Karahlyn Holdren
keholdren@geisinger.edu
570-522-6295

Thank You!
Autism BrainNet

Alycia Halladay
What have we learned from brain tissue studies?

Brain cells in people with autism have greater spine densities – too many connections

*Hutsler and Zhang, 2010*
How can you learn more?

Visit takesbrains.org and sign up to receive quarterly news and research updates.

Email us at info@AutismBrainNet.org

Follow us on Facebook and Twitter: @AutismBrainNet
Thank you for helping move research forward!

www.takesbrains.org

AutismBrainNet.org

Autism BrainNet is a program of SFARI