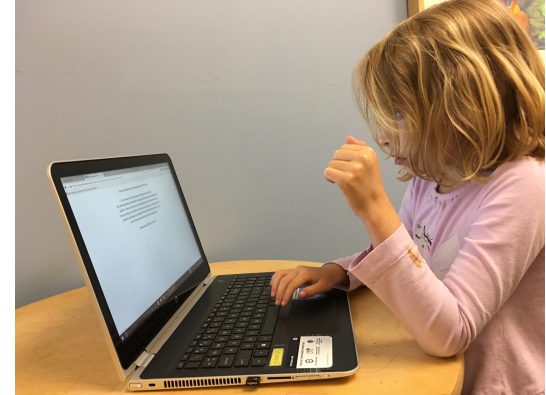


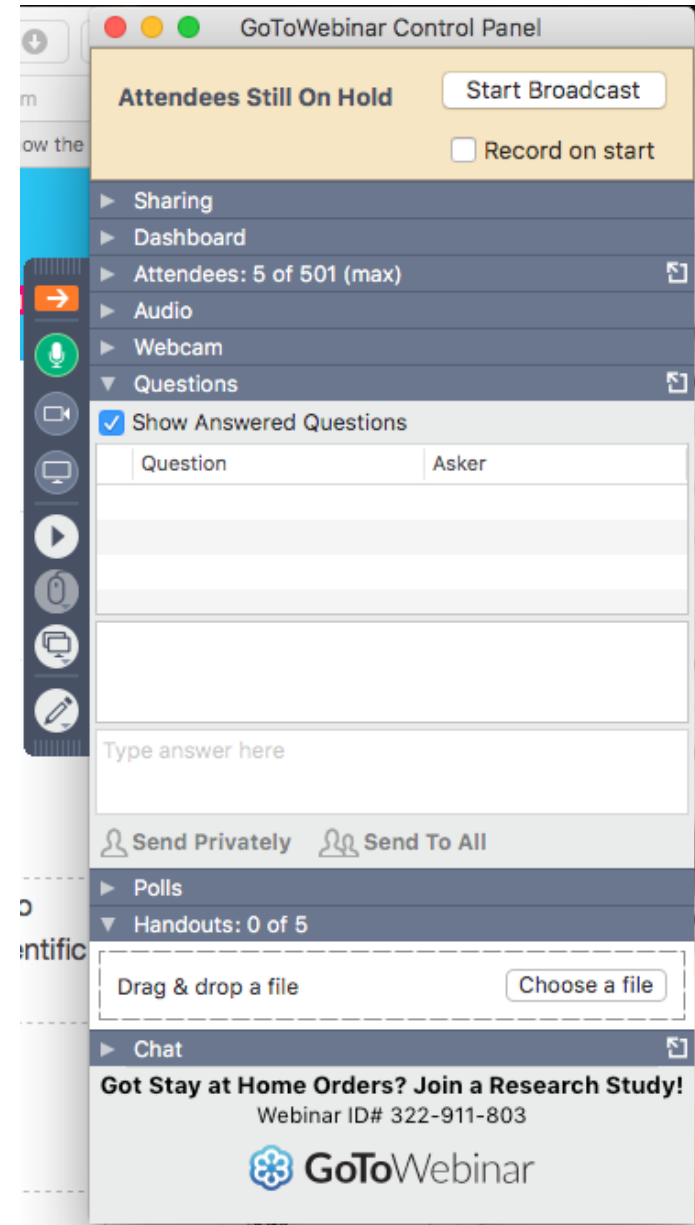
RESEARCH FAIR FOR FAMILIES

MAY 5, 2020



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



Online Developmental Screening Study

NOW RECRUITING RESEARCH PARTICIPANTS



Are you pregnant or have you had a new baby?

Learn about your baby's development!

Researchers at the UC Davis MIND Institute on the UC Davis Medical Center campus in Sacramento are conducting an *online* longitudinal developmental screening study of infants from 6 to 36 months of age.

Who can participate?

- Parents of infants younger than 6 months old

What does the study involve?

- Completion of up to six brief *online* screening sessions until your child is 36 months old
- An in-person visit at the MIND Institute at 24 & 36 months if there are any developmental concerns about your baby.
- Families will receive \$25 reimbursement for each completed online session and \$50 for a visit to the MIND Institute

What else can be expected?

- Close tracking of your baby's development with feedback from experts

Sign up for research

Learn more about the study by calling **916-703-0453** or visiting **StudyPages**:

<https://studypages.com/s/online-developmental-screening-study-892139/>



Additional information

All sessions will take place online.

The UC Davis MIND Institute is a collaborative international research center, committed to the awareness, understanding, prevention and care of neurodevelopmental disorders. Visit our website at mindinstitute.ucdavis.edu.



UC DAVIS
MIND INSTITUTE

Online Developmental Screening Study- Northern California – Chandni Parikh



Infant Social Motivation – typically developing- Natasha

*Parents of Infants Are Needed for a **Research Study!***

Parents are needed to provide information about the feasibility of an infant social motivation scale as a potential screening tool for Autism Spectrum Disorder (ASD).

You may qualify to participate if you are a parent of a typically developing infant who is 6-12 months old.

Participation includes:

1. 2 brief online surveys (about 1 year apart)
2. \$5 Amazon gift card for each survey

To participate, please email Savannah at:

s.davis@wustl.edu

Questions?

Contact Savannah:

(314) 362-4209

s.davis@wustl.edu


Washington
University in St. Louis
SCHOOL OF MEDICINE



Tell your friends!!



INFANT
BRAIN
IMAGING
STUDY

**Have a child with autism and a new baby?
Get paid to participate in research from home!**

Who do we need?	<ul style="list-style-type: none"> Families who have a child or children with autism <i>and</i> a new baby 6-months of age or younger Infants and child with autism must share same mom and dad
What do you get?	<ul style="list-style-type: none"> \$50 compensation for completion of remote data collection for each timepoint A detailed results report of your infant's development
What's the point?	<ul style="list-style-type: none"> Identify autism earlier Earlier identification means earlier intervention and improved outcomes

We are actively recruiting 250 infants who have older siblings with autism to participate in brain and behavior development research. Participation occurs when infants are 6-months, 12-months, and 24-months old.

During the uncertain time of the COVID virus, we are currently not able to complete in person research visits. However, we would very much like to include new families performing as much of our research as possible. This would include questionnaires completed online and phone interviews.

Once this crisis has passed and families are able to safely travel to study sites for in person visits, we may be in contact with you regarding opportunities for future participation which could include in person testing. Some families will be asked to continue future visits with remote data collection only.



University of Washington in Seattle
ibisstudy@uw.edu
206-543-2125

University of Minnesota
ibis@umn.edu
612-624-4533

Children's Hospital of Philadelphia
ibis@email.chop.edu
267-425-1727

Washington University in St Louis
ibis@wustl.edu
888-845-6786

University of North Carolina
ibisnetwork@cidd.unc.edu
919-843-1331

Contact the study site near you!
www.ibis-network.org

FOR IRB USE ONLY
IRB ID #: 201901013
APPROVAL DATE: 04/28/20
RELEASED DATE: 04/28/20
EXPIRATION DATE: 02/09/21

Infant Brain Imaging Study – Alicia, Lisa and Tess



Family Routines Intervention

for children with social communication difficulties

We are **actively enrolling** young children and their mothers to participate in a **free social communication intervention** with the Developmental Studies Laboratory at **Purdue University!**

In this **parent-mediated intervention**, families are provided with supportive strategies to foster their child's social development during **everyday family routines** (e.g., feeding, diaper changes, indoor play). Each treatment session/week focuses on one routine and how to facilitate social communication development.

Eligibility: Any child developing at risk between 6 months and 6 years. No formal diagnosis is required.

Enrollment options for summer 2020:



Home-based: Occurs at any time during the year that is most convenient for each family. Families spend 8 weeks incorporating strategies as presented in the activity kit at their own pace, with weekly check-ins from the research team.



Telehealth: Up to eight one-on-one 45-minute private sessions scheduled during the summer under the supervision of a licensed speech-language pathologist and team of graduate clinicians for Indiana residents.

All participating families will complete a series of virtual home visits and paperwork. Telehealth fees associated with these services will be paid by the research team. All families will receive a hard-copy of the activity kit for their use and a developmental summary at the end of the program.

If you know of families that may be interested in this intervention, please share this flyer and/or our contact information:



Parents of Children with Autism Needed for a Research Study

Stanford University researchers are recruiting children with Autism Spectrum Disorders and their parents to participate in a research study examining the effectiveness of a Telehealth delivery model for Pivotal Response Treatment (PRT) for improving communication abilities in young children with autism

Participants must:

- Have a child diagnosed with an Autism Spectrum Disorder between the ages of 2 and 5 years
- Meet inclusion based on behavioral screening, questionnaires and home video
- Be willing to complete a 12 week research treatment program via video conference

There is no cost to participate in this research study.

For More Information, Call
650-736-1235

For general information about participant rights, contact 1-866-680-2906

Pivotal Response Treatment Online – Grace Gengoux



Autism and Developmental Disorders Pivotal Response Treatment Research Program

autism.stanford.edu



Existing Line of PRT Research (Hardan et al., 2015; Gengoux et al., 2019)

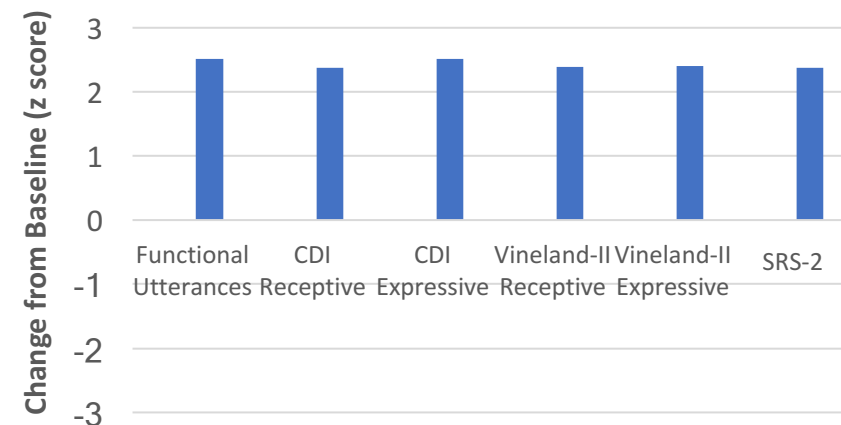
Pivotal Response Treatment (PRT) is an established treatment for ASD
Parent training is effective and can improve child social communication skills

Telehealth Trial is an Important Next Step

Pilot data (N=8) indicated viability of
PRT parent coaching delivered via video

*A Telehealth Delivery Model for PRT
has not been tested in a controlled trial*

Response to PRT-Telehealth Pilot (N=8)



PRT-T Trial Design

Eligibility Requirements

2 to 5-year-olds with ASD
and significant language delay

- Living in US, with internet access
- Primary language: English
- Medically stable, able to vocalize
- No more than 60 min 1:1 speech therapy and <15 hrs in-home ABA

① Assessment

Video with parent at home
Diagnostic records and interview
Parent questionnaires



② Randomization

either **PRT-T** or **Delayed Treatment** (12-weeks)

③ PRT-T Treatment

12 parent sessions (60 minutes) via video conference

Week 1: overview of PRT

Weeks 2-8: practice with feedback

Weeks 9 & 10: video review

Weeks 11 & 12: practice with feedback

For More Information, Call 650-736-1235
or email autismdd@stanford.edu

Telehealth Evaluation of Development for Infants

We are seeking feedback from families on a new telehealth-based assessment of infants' development.

Who can participate?

We are recruiting families:

- With Infants between the ages of 6-12 months, whose parents are concerned about their social interaction or communication
- With access to internet-enabled video-device (smartphone, tablet, computer)
- Willing and able to complete online questionnaires and complete a play-based assessment with their infant while coached over tele-health 5 times over the course of one year.

What does the study involve?

Families will be screened over the phone, and eligible families who decide to enroll will:

- Complete online questionnaires about your infant and about the telehealth sessions
- Participate in 5 online telehealth sessions with a member of the study team and their infant.
 - Each telehealth session last approximately 1 hour and involves different play activities conducted in your own home.
- All study activities will occur in your home, no travel to the MIND Institute is required

What else is expected?

- Families will receive written reports from standardized questionnaire measures
- Participants will be compensated \$25 for their time for each session.



Learn more about this study

For more information about this study, please contact Jennica Li research study coordinator at 916-734-8043 or hs-tedistudy@ucdavis.edu

Join our research registry

The Research Volunteer Registry is our database that matches potential participants with research studies. In this way, you can learn about other studies that match your child's age and diagnosis.

To register, please visit: vr.ucdmc.ucdavis.edu.

Additional information

The UC Davis MIND Institute is a collaborative international research center, committed to the awareness, understanding, prevention and care of neuro-developmental disabilities.

All studies take place at the MIND Institute, located at 2825 50th St. Sacramento, CA 95817

Telehealth Evaluation of Development for Infants – Meaghan Talbott

The TEDI Study

Meagan Talbott

UCDAVIS
HEALTH

MIND
INSTITUTE

For infants with early ASD symptoms and their families,

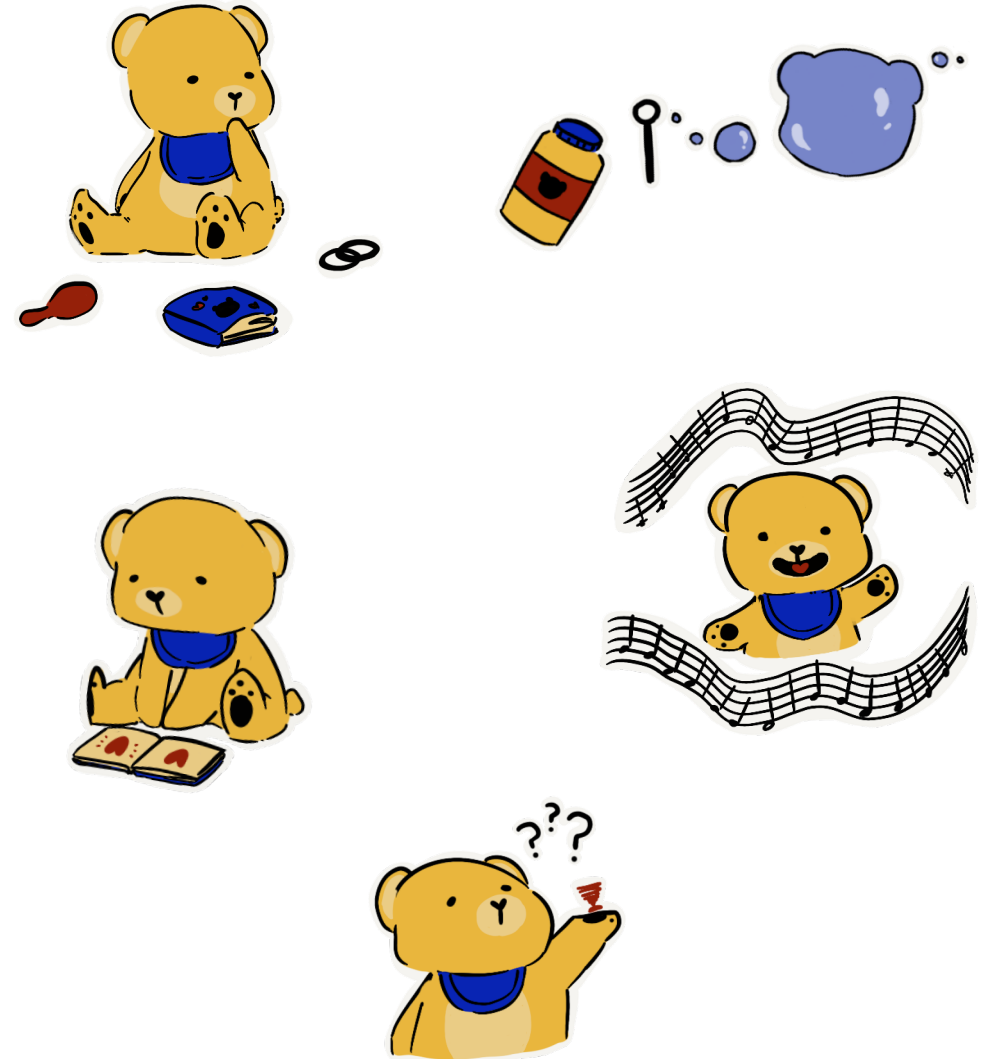
- Limited community resources for evaluation
- Unclear diagnostic outcomes
- Mixed findings for early treatments



Our Goal: Develop and validate telehealth-based assessment of infants

Participation in TEDI involves:

- Online questionnaires (30 – 45 minutes)
- Telehealth session (1 hour)
 - We will send toys
 - Coach parents through specific play activities
 - Use zoom, HIPPA-compliant
- Families receive a brief report with suggestions for how to support the skills their babies are working on
- 5 sessions over one year



Eligibility:

- Infant between 6-12 months
- Caregiver concerns about social communication
- Have a smart phone or device capable of running video session
- Live in US
- Primarily English-speaking
- No major motor, vision, or hearing impairments



To sign up:

Email hs-tedistudy@ucdavis.edu

<https://studypages.com/s/tedi-telehealth-evaluation-of-development-for-infants-728241/>

Many Thanks!

- Collaborators

- Sally Rogers
- Sarah Dufek
- Greg Young
- Jennica Li
- Maya Raj
- Raechel Paterson
- Lonnie Zwaigenbaum
- Susan Bryson
- Isabel Smith
- Jessica Brian

- Especially to the families and infants who have volunteered their time

- Funders

- NICHD R21HD100372 (PI: Talbott)
- Department of Psychiatry and Behavioral Sciences, UC Davis Tupin Award



Eunice Kennedy Shriver
National Institute of
Child Health and
Human Development

Do You Have a Child with Autism?

Seeking children with autism to participate
in the online **FRIENDS** research study



What Do Children Expect and Want From Their Friends?

We are interested in learning about
what your child thinks about their
friendships!

Your child may be eligible if he/she:

- Is between the ages of 8-11
- Is in grades 3-6
- Children with and without autism spectrum disorder are welcome to participate

Participation Involves:

- A 1-hour virtual assessment over videoconference (via Zoom).
- The assessment will include:
 - A brief child interview
 - Child questionnaires
 - Parent questionnaires

Participants will receive:

- A \$10 Amazon gift card



**If you are interested in
participating or would like more
information please contact the
study team directly:**

Melanie Feldman, M.A.
Principal Investigator
UMBFriends@gmail.com
(617) 800-9649

**QR complete the following survey
by following the QR code or link
below:**



<https://www.surveymonkey.com/r/X2MMQZ2>

FRIENDS – Melanie Feldman

www.surveymonkey.com/r/X2MMQZ2

UMass Boston IRB #2019084





Heather Joy Nuske
Penn Center for Mental Health
University of Pennsylvania

How Families with Children and Adults with Special Needs are coping with the COVID-19 Pandemic: An International Online Study

Principal Investigators

Prof. Andrea Samson & Dr. Daniel Dukes, University of Fribourg & UniDistance (CH)
Dr. Jo Van Herwegen, UCL Institute of Education (UK)

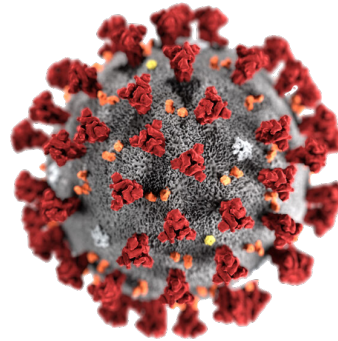
TAKE PART IN A NEW STUDY ON HOW PEOPLE WITH SPECIAL NEEDS COPE WITH THE COVID-19 CRISIS

What is the study about?

The aim of this international research project is to find out how individuals with special needs are coping with the Covid-19 pandemic and all its repercussions. Indeed, we are interested in learning about what is unique to their and their parents' experience of the pandemic.

Who can participate?

Parents of people (children or adults) with **Special Needs** (e.g. Autism Spectrum Disorder, Williams Syndrome, Down Syndrome, etc.).



What will you be required to do?

Answer a **questionnaire** about how you and your child are experiencing the pandemic, in terms of health issues, coping with stress and social distancing, etc. It is completely **anonymous** and will take you about **30 minutes** to answer.

Why is this study and your participation useful?

This study would contribute to a better understanding of the experiences and feelings of people with special needs and of their parents, thus informing the design of future interventions to improve their quality of life.

Please follow this link to participate or for more information: www.specialneeds covid.org

contact: emotion@unidistance.ch

Prof. Andrea Samson & Dr. Daniel Dukes, University of Fribourg & UniDistance (CH)
Dr. Jo Van Herwegen, UCL Institute of Education (UK)

Grandparents Study- Natasha Marrus



ACTIVE AUTISM STUDIES

Study to Explore Early
Development - Phase 3

Adult Sibling Survey for
Parents

Second Generation Survey
Project for Grandparents

Grandparent Survey

- Do you have a child with an autism spectrum disorder?
- Do you also have grandchildren?

If yes to both, then this study is for YOU.

The risk that autism will affect grandchildren in families like yours is unknown, and this brief survey is designed to gain new knowledge about the level of risk, and which second generation offspring might benefit from early intervention.

Please note that

- » All of your information will remain confidential (only your IP address is logged to prevent duplication of data),
- » There is no cost to participate, and
- » You will have the option to provide your contact information so we can tell you about further opportunities for study participation (which include compensation).

Before starting the survey, please answer 2 screening questions to determine if you are eligible. If you are eligible for the study, you will next be asked to review the informed consent language and then give consent at the beginning of the survey.

sdslab.wustl.edu/grandparents



SPARK – Amy Daniels



[ABOUT](#)

[RESEARCH](#)

[DISCOVER](#)

[NEWSLETTER](#)

[JOIN US](#)

[LOGIN](#)



What is SPARK?

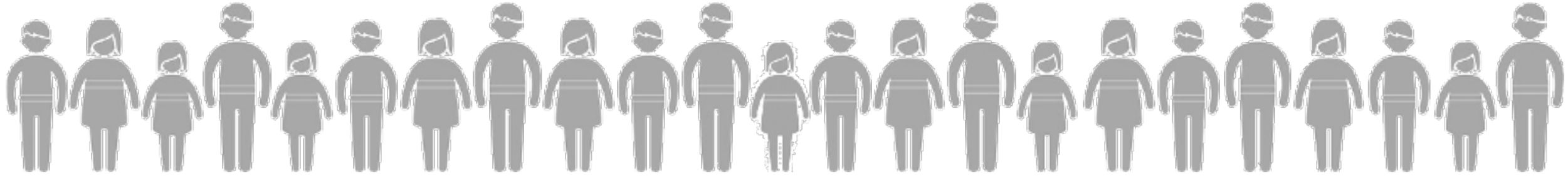
SPARK, launched nationally in April 2016, is a large, online research study that aims to **recruit, engage, and retain** a community of at least **50,000 individuals with ASD and with their family members** to:

- Identify the causes of autism
- Accelerate clinical research by providing the research community with a clinically- and genetically- characterized cohort of consented, re-contactable participants

We are a research community of over **230,000** individuals!



Who is eligible to participate?



The entire autism community is invited to join.

Families and individuals with autism are eligible to join SPARK if they:

- 1 Live in the United States
- 2 Can read and understand English
- 3 Are an independent adult with ASD, or the parent of a child or dependent adult with ASD. Biological siblings are welcome too
- 4 Have a professional diagnosis of autism

—SPARK—
Enrollment
and
Participation



Step 1

Create an account online



Step 2

Invite family members



Step 3

Complete and return
your saliva kit



Step 4

Discover new research
opportunities

Research match
findings

SPARK

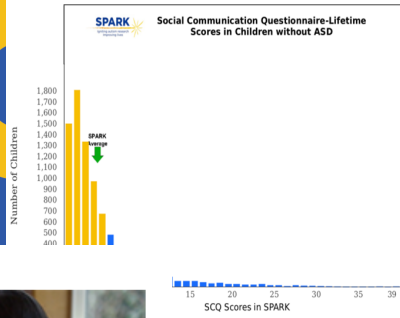
FEATURES

SPARK SNAPSHOT
Independent Adults with Autism

Data from December 2015 to April 2018

Did you know that as of April 2018,
34,214
people with autism have participated
in SPARK?

Individual behavioral
reports



FAMILY STORY | 2:53

Lynn Vigo recently received a genetic result from SPARK.

...filled out a series of questionnaires about your child Joseph's behavior. The results of the **Social-Communication Questionnaire (SCQ Lifetime version)** for children without Autism Spectrum Disorder in SPARK. According to your **low number of social, communication and other behavioral**

clinical and research tool that measures **social, communication and other** that are commonly present in ASD, such as difficulties with play or children. It is often used by researchers to confirm the presence of signs of autism. The SCQ asks about behaviors in early childhood as well as present concerns reported by the parent is summed to make a total score.

What
—SPARK—
Gives back



RESEARCH | 2:13
Raphael Bernier, Ph.D. discusses his research and why he's excited about SPARK.



WEBINARS
Dr. Wendy Chung describes basic concepts in autism genetic research.
[More](#)



FAMILY STORY
Learn more about how Lynn used SPARK.
[More](#)

Potential to receive a genetic result

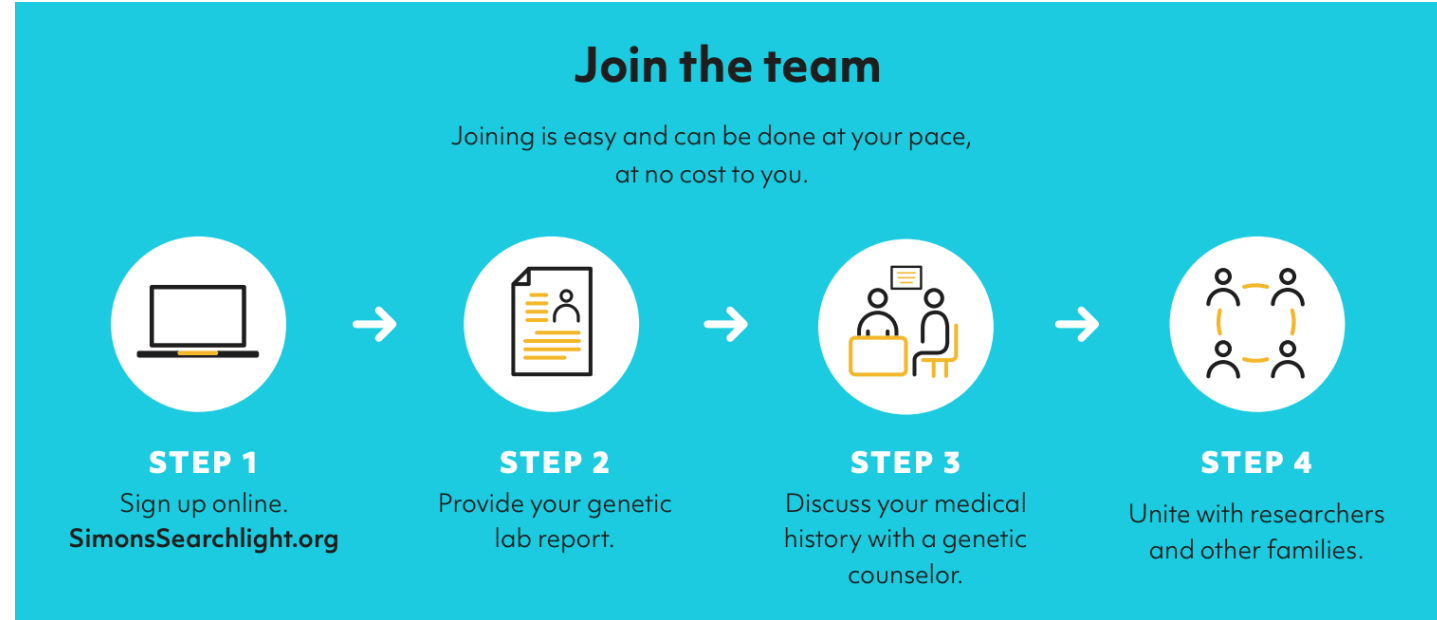
To learn more or join, visit: www.SPARKforAutism.org



@SPARKforAutism

Simons Searchlight

This study aims to better understand genetic neurodevelopmental conditions, specifically those associated with ASD



Over 3000 families have registered so far!

Are you eligible?

- Check our list of genes we study at www.SimonsSearchlight.org (200+)
- Accepting individuals speaking either English or Spanish

Autism BrainNet – Cyndi Schumann



ALEX PLANK IS A FILMMAKER, ACTOR, FOUNDER OF WRONGPLANET.NET, AND A SUPERHERO. HE WAS DIAGNOSED WITH ASPERGER'S SYNDROME AT AGE 9.

IT TAKES BRAINS TO SOLVE AUTISM

Alex Plank never saw himself as super. More like "awesome" really. He feels that being on the autism spectrum is a gift, and he wants to share that gift with scientists so they can understand what makes his brain unique.

Many think Alex and others just like him are super heroes. Why?

They've all been united by one brave and heroic act... pledging to donate their brain tissue to science when they are, sadly, no longer with us. It's difficult to think about, but the reality is that brain tissue is urgently needed for the scientific research that will help thousands of people with autism.

So join Alex to help ensure a brighter future for all. Because it takes brains to solve autism.

Visit TakesBrains.org to learn more.



This initiative is guided by:





Cynthia Schumann, PhD
Director, Autism BrainNet
UC Davis M.I.N.D. Institute
May 5, 2020



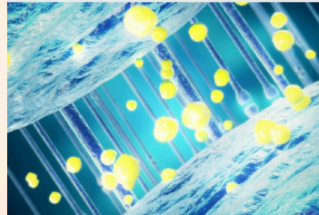
Promoting Research into the Causes of Autism Spectrum Disorder

Although there is substantial evidence from neuroimaging studies that the brain of a child with autism is undergoing abnormal development, little is known about the underlying cellular, molecular and genetic mechanisms that lead to the onset of autistic symptoms.

[READ MORE +](#)

The serotonin system in the autism brain

[READ MORE »](#)



latest news



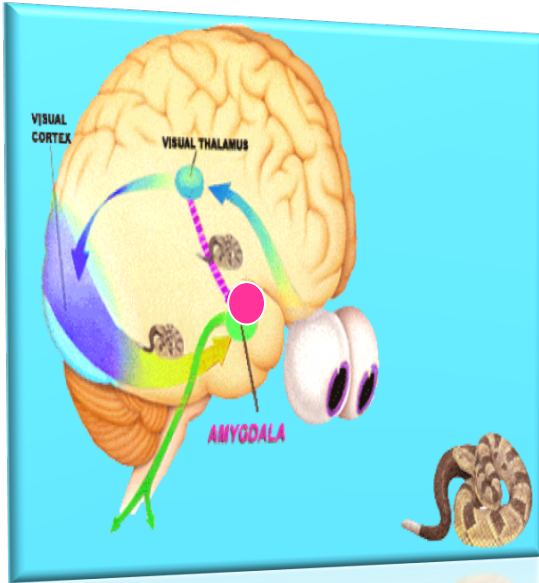
This initiative is supported by:

SFARI SIMONS FOUNDATION
AUTISM RESEARCH INITIATIVE

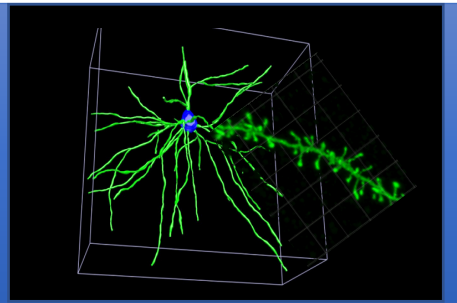
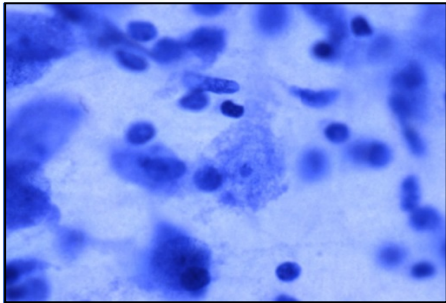
Facilitate innovative, high-quality brain tissue research:

- To improve the understanding of the biological causes of autism and related neurodevelopmental disorders
- To help identify indicators for autism (biomarkers) that could later be applied to diagnosis and treatment
- To help identify therapeutic targets

Neurobiology of anxiety in people with ASD



- Brain areas that modulate social behavior and emotions, such as the Amygdala, continue to grow and change well into adulthood.
- Amygdala works as a “danger detector”, searching for clues in the environment. Altered Amygdala function could cause anxiety, a common feature of ASD.
- The Amygdala in people with ASD does not undergo the same growth trajectory – increased size and # of neurons and connections in childhood, followed by fewer neurons and connections in adulthood.
- If we understand how cellular mechanisms in the Amygdala are changing throughout life, we have the opportunity to change course and discover novel treatments.



PNAS

Neuron numbers increase in the human amygdala from birth to adulthood, but not in autism

Thomas A. Avino^a, Nicole Barger^a, Martha V. Vargas^a, Erin L. Carlson^a, David G. Amaral^{a,b,c}, Melissa D. Bauman^{a,b}, and Cynthia M. Schumann^{a,1}

^aDepartment of Psychiatry and Behavioral Sciences, UC Davis MIND Institute, School of Medicine, University of California, Davis, Sacramento, CA 95817; ^bCalifornia National Primate Research Center, University of California, Davis, CA 95616; and ^cCenter for Neuroscience, University of California, Davis, CA 95618

Edited by Joseph E. LeDoux, New York University, New York, NY, and approved March 1, 2018 (received for review February 12, 2018)

Learn more and stay connected



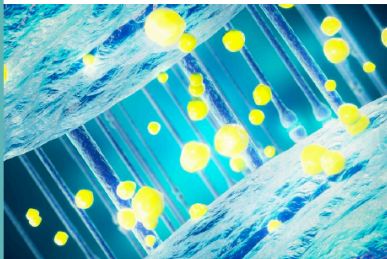
April 30, 2020

Message from David Amaral, Scientific Director of Autism BrainNet

We hope that you, your family, and your friends have been spared by the coronavirus. Of course, many thoughts go through one's head when you experience something as frightening as this pandemic. It reminds me of how much science still needs to be done in order for us to understand our world and to overcome the many threats that still remain. [Read more.](#)

SCIENCE

The serotonin system in autism



Serotonin helps to control social behaviors and body functions such as mood, sleep, and appetite. It also plays an important role during brain development. Results from a new study show that changes in serotonin function in autism may be specific to receptor type and brain region.

[Read more about this research.](#)

Visit:

AutismBrainNet.org and sign up to receive news and research updates.

Email us:



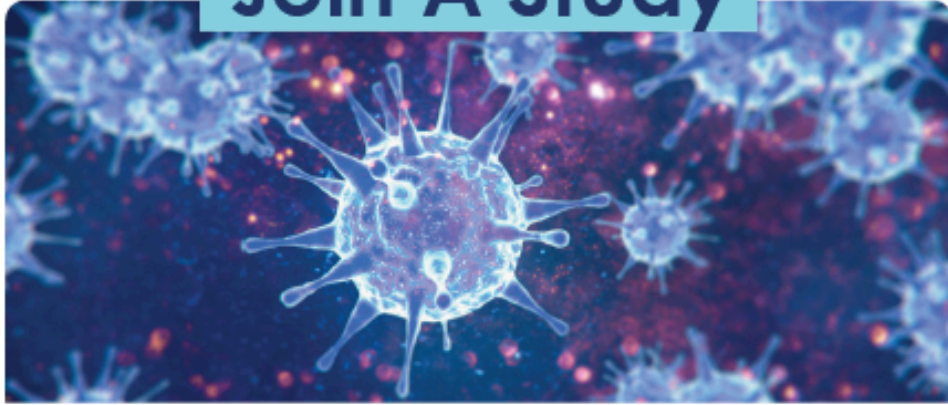
info@AutismBrainNet.org

Follow us on social media:



@AutismBrainNet

Join A Study



Mental Health Impact of COVID-19 Pandemic Study

The purpose of this study is to learn about how stressors related to the COVID-19 virus affect mental health over time. We hope to better understand the experiences of participants during this difficult time.

Participation involves completing online questionnaires every two weeks, for 6 months.

- The questionnaires take about 20 minutes to complete.
- You must be at least 18 years old to participate.
- Participation is voluntary, and you may withdraw at any time.
- Compensation is not provided.

To participate in the study visit:

nimhcovidstudy.ctss.nih.gov



National Institute
of Mental Health

Questions: Call 240-665-0697 or email NIMHResearchVolunteer@nih.gov

Mental Health Impact - Alycia



Thank you for joining us!

This presentation will be online on the ASF COVID-19
webinar page

The recording will also be available

Lists of research studies with links can be found on the ASF
participate in research page

We will be doing this again with different studies.

ahalladay@autismsciencefoundation.org

