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

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.

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

Tell your friends!!
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.

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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:

AJ Schwichtenberg, PhD
Developmental Studies Laboratory
ajlab@purdue.edu 765-494-6610
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
**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)**

- **Change from Baseline (z score)**
  - Functional Utterances Receptive
  - CDI Expressive
  - CDI Receptive
  - Vineland-II/II Receptive
  - SRS-2 Expressive

- **Graph showing**
  - Positive changes in various social communication metrics after PRT-Telehealth intervention.
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

Assessment
Video with parent at home
Diagnostic records and interview
Parent questionnaires

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

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-teledistudy@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.ucdm.ucdavis.edu.

Additional information
The UC Davis MIND Institute is a collaborative international research center, committed to the awareness, understanding, prevention and care of neurodevelopmental disabilities.

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

Meagan Talbott
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

Many Thanks!

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

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

• Especially to the families and infants who have volunteered their time
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:
  o A brief child interview
  o Child questionnaires
  o 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

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

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

Do You Have a Child with Autism?
Seeking children with autism to participate in the online FRIENDS research study

UMass Boston IRB #2019084
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)
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.

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.

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

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.specialneedscovid.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
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.
SPARK – Amy Daniels
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

Potential to receive a genetic result

Research match findings

Individual behavioral reports

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

SPARK SNAPSHOT
Independent Adults with Autism

Features

What
—SPARK—
Gives back
To learn more or join, visit: www.SPARKforAutism.org
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
Cynthia Schumann, PhD
Director, Autism BrainNet
UC Davis M.I.N.D. Institute
May 5, 2020
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
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.
Learn more and stay connected

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

Email us: info@AutismBrainNet.org

Follow us on social media: @AutismBrainNet

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.
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

Questions: Call 301-443-1122 or email NIMHResearchVolunteer@nih.gov
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