Welcome!

You are receiving this newsletter as part of your participation in the Infant Sibling Study at the MIND Institute. We hope you enjoy this update on our recent findings and new research efforts. Please feel free to share this information with family and friends. We greatly appreciate all you have done for our study over the years!

Infant Sibling Study: Phase III

After the first 10 years of our study, we were fortunate to renew our funding for another 5 years. In addition to continuing to identify early red flags for autism spectrum disorder (ASD) in infancy, the goals of the newest phase of our study are to:

- Identify the earliest signs of ADHD in infancy by recruiting infants who have an older sibling with ADHD, and following them from infancy through 3 years of age.
- Develop a new video-based method for detecting ASD in infants.
- Follow the original two groups of children, re-testing them between the ages of 6 and 11 years to look for learning disabilities, ADHD, and other challenges that may become apparent only as children get older.

The ultimate goal of the Infant Sibling Study is to find warning signs of autism and ADHD in infancy so that we can make diagnoses, and help children get treatment, earlier.

— SALLY OZONOFF, PH.D.
Principal Investigator
MIND Institute Infant Sibling Study

The UC Davis MIND Institute is a collaborative research center committed to the awareness, understanding, prevention, care and cure of neurodevelopmental disorders.
What have we learned so far?

Over 400 children have participated in the first two phases of the study. Because of your family's participation, we have made many important discoveries.

**Recurrence risk of ASD**

Previous estimates of autism recurrence risk, based on data from the 1980s, were 3 – 5%. In collaboration with an international team of researchers — the Baby Siblings Research Consortium — we recently examined the risk of having a second child with ASD if a family already had one child on the spectrum. Our findings suggest that the risk of recurrence may be as much as four times higher than previously estimated, with an overall recurrence rate of between 15 – 20%.

### Delayed development in siblings of children with ASD

In another paper, we assessed the frequency of delayed social communication, motor, language, and cognitive development in the siblings of children with ASD who did not develop ASD themselves. We found that 28% of younger siblings of children with ASD displayed delays in their development by the time they were 3 years old. These delays were evident by the time these children were 1 year old. This study showed that not all siblings who show early delays will go on to be diagnosed with ASD, and that even if they don't develop ASD, some younger siblings will have other challenges that may need treatment.

### Potential biomarkers for ASD?

Fifty-five families participated in a supplement to the Infant Sibling Study that used MRI to learn about the brains of infants who later develop ASD. Infants who were later diagnosed with ASD had more cerebrospinal fluid by 6 to 9 months of age. This raises the possibility that these brain anomalies may serve as biomarkers for the early identification of ASD, perhaps even before behavioral symptoms emerge.

Phase III: New development of a video-based method for identifying autism in infants

Thanks to a $450,000 grant from Autism Speaks and a generous private donation from a local family, we have recently developed a video-based autism screening measure, the Video-Referenced Infant Rating System for Autism, or VIRSA.

This tool involves the use of a secure, confidential website where parents can view videos depicting children with a range of behaviors, selecting videos that are most like their child. A large grant from the National Institute of Health is allowing us to test the usefulness of this tool in identifying autism earlier.

The hope is that this will allow us to identify autism risk at a younger age, offering the opportunity for intervention before full symptom onset. The VIRSA has potential for much wider use than existing measures that rely upon visits to health care providers. Since it is intended for internet administration, it will cost less than tests that require clinic visits, won't require the lengthy waits for appointments that are typical of most clinics, and will be available to families who live far from medical centers.

Families in the current phase of the Infant Sibling Study are helping us test whether this tool accurately identifies autism at early ages.

The VIRSA aims to identify autism risk at a younger age than is currently possible.
Where are you from?

You have come from far and wide to participate in our study. Some families have even traveled from other states!

Quick facts

- Nearly half of the families in the study traveled more than 25 miles one-way
- Several families traveled over 200 miles to participate
- Families from the Northern California region traveled from over 20 different counties

Counties of origin for participating families from the Northern California region.

Expanding our horizons

In addition to studying the earliest signs of ASD, a new addition to the Infant Sibling Study also hopes to identify ADHD earlier. ADHD is one of the most common diagnoses of childhood. Earlier diagnosis could result in earlier treatment and prevention of later problems in school.

Early signs of ASD

Over the last 10 years of our study, your family has helped us learn a great deal about the earliest signs of autism. These include:

- Limited eye gaze
- Lack of warm, joyful expressions
- Diminished sharing of interest or enjoyment
- Reduced response to name
- Lack of gestures such as pointing, showing, or reaching
- Unusual use of objects, such as staring at them for prolonged periods, rotating them, or spinning them
- Lack of words by 16 months

We have also become interested in understanding early signs of other conditions and have recently expanded our focus to include ADHD.

Detecting ADHD earlier

Children with ADHD are typically not diagnosed until they are 6 or 7 years old, making it difficult to provide interventions early. Because of this, we are expanding our Infant Sibling Study’s focus to also include the identification of early signs of ADHD in infant siblings of children diagnosed with ADHD.

This new study is one of the first in the world to focus on warning signs of ADHD in infancy. We are now evaluating the early development of infants who have an older sibling with ADHD.

About the Principal Investigator

Dr. Sally Ozonoff has directed the Infant Sibling Study for the past 11 years. She is an Endowed Professor and Vice Chair for Research in the Department of Psychiatry and Behavioral Sciences and the MIND Institute at UC Davis. Her current research focuses on onset patterns of autism, very early identification, and risk factors for regression in autism. Dr. Ozonoff has written over 100 peer-reviewed publications and chapters and is the author of three books on ASD.
It takes a team

The Infant Sibling Study team looks forward to hearing from you!

Our team
Our research would not be possible without the amazing families who participate, nor the dedicated lab staff. Thank you for being part of our team. We look forward to seeing you at your next visit or the annual Thank You Party.

Project Director
Sally Ozonoff, Ph.D.

Lab Manager
Monique Moore Hill, M.S.

Research Team
Michelle Ahronovitz
Ashleigh Belding, M.P.H.
Elise Phelps Hanzel, Ph.D.
Alesha Hill
Ian Kyle
Meghan Miller, Ph.D.
Simone Phillips
Mary Beth Steinfeld, M.D.
Gregory Young, Ph.D.

Are you moving?
Please let us know if you are moving or changing your contact information. Contact Alesha Hill at 916-703-0297 or ahill@ucdavis.edu.

We need your help!
We are always looking for new families to participate in our studies. If you know any families who have infants, and who also have an older child with ASD, ADHD, or typical development, please tell them about our study!

Save the date!
The annual MIND Institute Thank You Party will be held on:
Saturday December 6th, 2014 1 – 4 p.m.
UC Davis MIND Institute
We hope we see you there!