INFANT BRAIN IMAGING STUDY

2025 Newsletter

If you see this icon, you can watch a video of this news item on our new IBIS YouTube channel. Each story icon will take you to that story's video.

IBIS Is Still Recruiting New Infants Who Have an Autistic Sibling

The IBIS Network has been studying early infant brain and behavior development in autism, Down syndrome, and Fragile X for nearly 20 years. This work has already had a huge impact on the field in informing improved diagnosis and interventions for autism. To-date, over 1,000 infants have participated in IBIS and this cohort of infants has helped us learn more about supporting cognitive, social, emotion, and motor development in children.

One of our current goals is to replicate prior findings from our previous cohort that could lead to an MRI-based early detection tool for autism. To-date, we have recruited over 200 infants for this replication study. We are in our final push to identify 50 more infants who can help us be successful in meeting this goal.

If you have a child under 6 months who has a full sibling with autism, please contact us, as we would be eager to discuss enrolling your family in the study. (Or if you know someone who does, encourage them to reach out). In addition to compensation, families receive summaries of developmental testing.

We appreciate any help you can provide towards meeting this critical goal in advancing research in autism!

Learn More/Contact us here:

https://ibis-network.com/infant/

Baby Talk: Your Words Are Building Blocks of Development

Part of the IBIS Protocol for infants with an autistic sibling includes an optional component for families to complete at-home language recordings via devices developed by the Language Environment Analysis (LENA) Research Foundation. Dr. Meghan Swanson, at our University of Minnesota site, has been leading this research. Families complete recordings at 6, 12, and 18 months of age through a wearable recording device. The recordings start with 10 minutes of play between parent/child and the device continues to record the infant's babbling and parent interactions throughout the day. While staff listen to the first 10 minutes of each recording, automated computer algorithms analyze the remaining recordings to estimate infant babbling and the amount of caregiver speech they hear.

Research has shown that parents can improve language skills by talking to their infants in the first year of life. From our prior analysis in IBIS, we've discovered that infants who heard the most caregiver speech early on had the best language skills at age 2. The positive effects of talking to babies was found for both infants who went on to have autism and those who did not.

We are now working to collect home language data on a new set of babies with the goal of determining if sounds that infants make can help predict which children will benefit from language intervention. We also want to understand which types of caregiver speech best supports early language skills.

All families enrolled in IBIS are invited to participate! If you are interested in learning more about LENA, please reach out to Samantha Smalley at lena_ibis@umn.edu. If you are interested in learning more about our past research on language development, you can review two recent publications on the impact of early language exposure as well as it's relation to white matter in the brain.

IBIS Joins New Multi-Project Effort to Study Down Syndrome

Last fall, IBIS was awarded a 5-year grant by the National Institutes of Health (NIH). Our project is part of the NIH INCLUDE Cohort Development Program. INCLUDE is a congressionally approved research directive that started in 2018 to encourage and channel resources across the NIH to DS research. This grant, which funded 5 different DS research projects across the lifespan, was structured in this way to develop a common protocol and ensure similar data collection across all projects that could benefit future researchers. The initial startup year for the grant, which involved development of the common protocol, is nearly finished. Each team has a Community Advisory Board which provides input from individuals with DS, their family members, and other community professionals. Recruitment for all projects is expected to begin later this fall. The 5 projects funded are:

- IBIS-DS: Enrolling 100 infants with DS and 50 controls to study neuroimaging and key domains of behavioral development during the first 2 years of life
- ALLY-DS: Enrolling 400 participants age 6+ to advance natural history of DS-related co-morbidities and their intersections with social determinants of health and structural ableism
- MET-DS: Enrolling 200 participants age 6-24 to deeply phenotype metabolic dysregulation, obesity, lifestyle, and the development of co-occurring health conditions
- DECODE: Enrolling 400 infants age 0-2 to better understand structural birth defects, hematopoietic development, and neurodevelopment in DS
- HTP-LAN: Enrolling 1500 participants across the US/Latin America to help define the clinical and neurodevelopmental profiles as well as biosignatures associated with differential features in Latinos with DS

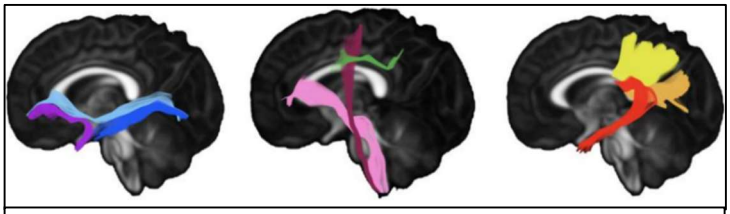
All sites will be collecting a common protocol that includes medical history, caregiver reporting, in-person testing, and biological samples. Depending on the specific study project, additional activities may include sleep studies, activity monitors, blood draws, and imaging. For more information on all projects, check out the CDP website at https://includecdp.org/. As we launch our own recruitment later this fall, you will be able to find more information on our IBIS DS website https://dsstudies.com/.

White Matter in Infants with DS: What We Know So Far

Very little brain imaging has been done to understand Down syndrome. IBIS was one of the first studies to begin research on early brain development in infants with DS. Since 2019, IBIS has been following infants with DS (and controls without DS) through the first 2 years of life with un-sedated MRIs and developmental testing. Our team recently published initial findings on white matter in the brains of infants with DS.

Important parts of brain development involve not only the neurons in the brain, but also the tracts (white matter) that connect those neurons. As the brain's wiring system, white matter links the different gray matter areas of the brain. Gray matter controls things such as movement, memory, and emotion.

Our study compared white matter between infants with DS and typically developing infants via Diffusion Tensor Imaging (DTI), which creates an atlas of the brain to study the tracts of white matter. What we discovered is that in infants with DS, white matter appears to have less structural integrity and reduced myelination, and neurites (extensions from the neuron's body) are less dense and more dispersed, which may contribute to cognitive and motor delays.

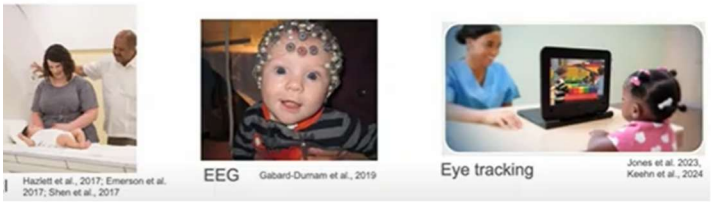


Sample white matter tracts that were analyzed in infants with DS.

This research lays a foundation for future research on white matter in DS, suggesting that continuing to follow these infants later into childhood can help us learn more about white matter development and its relation to cognitive, behavioral and motor development in DS. You can access the published paper via this link.

Parent Perceptions on Autism Testing During the 1st Year of Life

If you knew your child had autism within the 1st year of life, what would you do to access early intervention services? As research progresses, some technologies such as MRIs, EEGs, and eye-tracking could eventually allow for an earlier diagnosis for autism. While most parents agree they would want to take advantage these future technologies as an impetus to seek out early intervention, questions remain about how families would approach seeking the best care for their child.



Dr. Kate MacDuffie (UW) conducted research with IBIS parents (who have previously had a child with autism and also have a new infant) alongside parents with a toddler and no autism parenting history to determine what gaps might be in approaches to seeking intervention. The parents with prior autism experience had a much higher expectation of seeking out speech, occupational, and physical therapy, Applied Behavioral Analysis, and early intervention supports. These parents are also more likely to seek out support from insurance/disability, whereas parents with no autism experience are likely to seek out information from pediatricians, information online, and in support groups.

While these results may seem intuitive, it raises several points of concern. First, for families who lack exposure to autism, navigating this new world of autism supports for their child have potential pitfalls. First, studies of pediatricians suggest they often feel unprepared to help families navigate the "black box" of autism care, and information online is not always trustworthy; for example, one study of TikTok videos with #autism found only 27% contained accurate information. Second, when these new early diagnostic technologies become available, it will be unclear at what point these tools can advance an official autism diagnosis that may aid in accessing disability or other insurance benefits; research teams will need be thoughtful about how they can connect families to resources for early interventions, clinical trials, and other supports. You can read the published paper here.

2025 IBIS Summer Interns

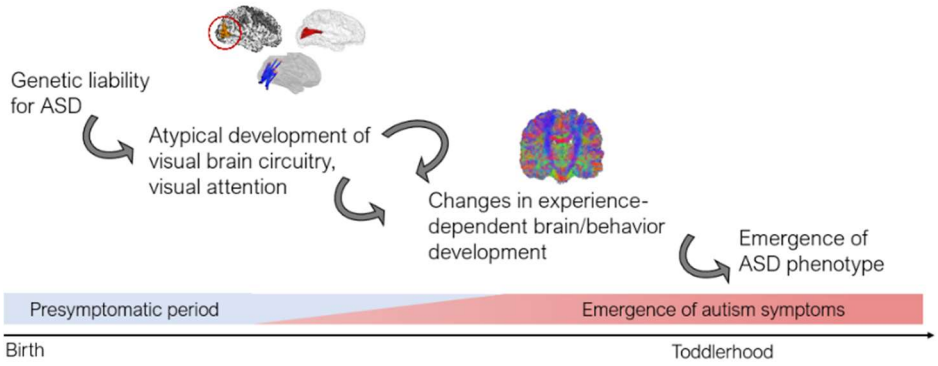
IBIS has an annual summer internship open to undergrad and graduate students, with the goal of exposing students to opportunities and careers in autism and DS research. Each student works under an IBIS faculty mentor and chooses a research goal for their experience. This year, IBIS had 2 summer interns:

Aldair Algueta-Vazquez is a Junior at UNC-Chapel Hill, majoring in Neuroscience and Biology. He worked this summer with mentors Drs. Becca Grzadzinski & Jose Rodriguez-Romaguera, focusing on gathering and analyzing eye tracking data from IBIS participants to understand the relationship between pupil response and social motivation in infants. Aldair is on the UNC Dean's list, is the oldest of 10 siblings, and wants to be a pediatric neurologist.

Miftahul Jannat is a Junior at the University of Minnesota, majoring in Psychology and the Philosophy & Sociology of Law, Criminology, and Justice. She worked this summer with Dr. Chimei Lee, focusing on analyzing IBIS questionnaire data to understand how autism traits run in families. Miftahul has earned a certificate in Autism Spectrum Disorders from UMN, has a brother who is autistic, and wants to be a physician working with families impacted by autism.

The Brain's Visual System: A Building Block on the Path to Autism

Over a decade of IBIS imaging studies have led to a better understanding of the brain's visual system and its link to autistic social behavior. In a recent paper, Dr. Jessica Girault (UNC) examined what we know about genetic liability for autism and early variations in the development of the brain, specifically highlighting the links between the brain's visual system and emergence of autistic symptoms.



By following infants who have an older autistic sibling through the first 2 years of life (many of which have now been followed into school age), we have learned more about the genetic risks for autism and the early changes in brain development that that lead to the emergence of autistic symptoms.

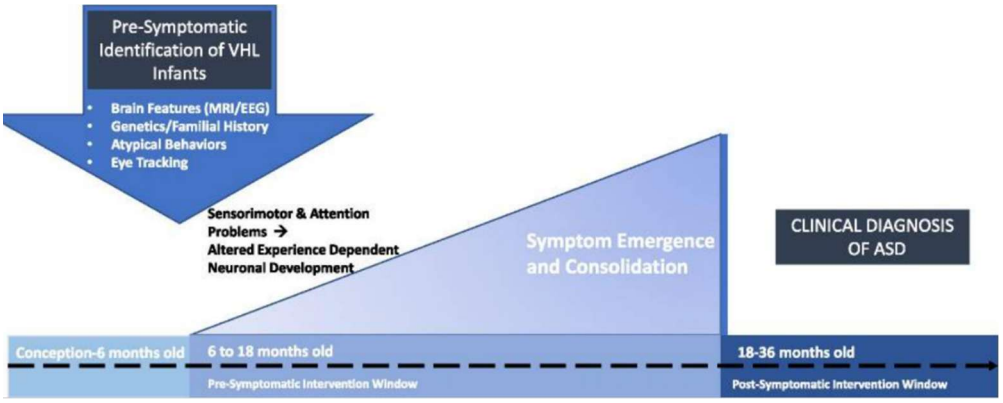
Genetic expression has a significant impact on the development of the brain's visual system starting in the first year of life including: atypical white matter, amygdala volume overgrowth, visual cortical surface area hyper-expansion, enlarged cerebrospinal fluid volumes, and weaker connectivity between the amygdala and visual cortex; IBIS has found that all of these have various associations with autistic symptoms. This research suggests that prior to the emergence of autistic symptoms, genetic liability leads to atypical developments in the brain's visual system that initiate a cascade of brain-behavior changes that, over time, alters the environment for social learning and gives rise to the emergence of the defining features of ASD. Through further research, we hope to identify avenues for early intervention may be able to improve these developmental trajectories around the brain's visual system. You can read Dr. Girault's paper here.

Helping Babies Early – Even Before Autism Symptoms Emerge

We know that early intervention in autism can improve a child's developmental outcomes, but what if we could identify supports for children before symptoms even emerge? As research identifies changes in brain development during the first year of life and those links to behavior continue to emerge, along with the tools to identify risk for autism prior to when a clinical diagnosis is given, the question of how research can inform supporting child healthy development becomes an important consideration for future autism research.

In a paper published in the Journal of Neurodevelopmental Disorders, Dr. Rebecca Grzadzinski (UNC) discusses a framework for what intervention and support might look like for children at-risk for autism during a pre-symptomatic window, defined as 6-18 months of age. Some of these activities might include guiding parents on healthy interactions with their infants that support optimal brain development through play, sharing attention, and helping them respond to sights, sounds, and touch.

Specific areas of focus would likely include sensory regulation, attention flexibility, motor skills, and social communication. The goal of these interventions would be giving an infant the best possible chance to grow and learn during the first few months of life, which represent a critical period of brain development.



Resource: Video Library Addressing Concerns in Autism

The Baby Siblings Research Consortium (BSRC) is a collaboration of many autism researchers (including IBIS) across North America studying autism through at-risk siblings. The BSRC website has several great videos put together by various researchers covering concerns around your child's development, concerns for autism, options for intervention, and what various testing may help you learn about your child. You can visit the following link to view these videos:

https://www.babysiblingsresearchconsortium.org/videos

Once on their website, you can also click "Resources" on the top right for links to other helpful tools, including other video resources, parenting tools, mental health supports, and tips for your child's education and free time.

New Peer-Reviewed Research from the IBIS Network

(with links to read to original publication)

Associations between early trajectories of amygdala development and later school-age anxiety in two longitudinal samples.
https://pubmed.ncbi.nlm.nih.gov/38154378/

Atypical functional connectivity between the amygdala and visual, salience regions in infants with genetic liability for autism.
https://pubmed.ncbi.nlm.nih.gov/38696599/

Brain volumes, cognitive, and adaptive skills in school-age children with Down syndrome.
https://pubmed.ncbi.nlm.nih.gov/39701965/

Development of Sensory Regions vs the Rest of the Cortex in Autism.
https://pubmed.ncbi.nlm.nih.gov/39412795/

Differential cognitive and behavioral development from 6 to 24 months in autism and fragile X syndrome.
https://pubmed.ncbi.nlm.nih.gov/38509470/

Etiologic heterogeneity, pleiotropy, and polygenicity in behaviorally defined intellectual and developmental disabilities.
https://pubmed.ncbi.nlm.nih.gov/38481128/

Infants who develop autism show smaller inventories of deictic and symbolic gestures at 12months of age.
https://pubmed.ncbi.nlm.nih.gov/38204321/

Multi-site EEG studies in early infancy: Methods to enhance data quality.
https://pubmed.ncbi.nlm.nih.gov/39163782/

The Relationship of Objectively Measured Sleep to Puberty in School-Age Children with Familial Autism
https://doi.org/10.1093/sleep/zsae067.0801

White matter development and language abilities during infancy in autism spectrum disorder.
https://pubmed.ncbi.nlm.nih.gov/38383768/

Commonly used genomic arrays may lose information due to imperfect coverage of discovered variants for autism spectrum disorder.
https://pubmed.ncbi.nlm.nih.gov/39266988/

White Matter Microstructure in School-Age Children with Down
Syndrome. Developmental Cognitive Neuroscience.
https://pubmed.ncbi.nlm.nih.gov/40043413/

Parent attitudes towards predictive testing for autism in the first year of life.
https://pubmed.ncbi.nlm.nih.gov/39154179/

Statistical properties of functional connectivity MRI enrichment analysis in school-age autism research
https://pubmed.ncbi.nlm.nih.gov/40022940/

Social motivation in infancy is associated with familial recurrence of ASD.
https://pubmed.ncbi.nlm.nih.gov/36189644/

Adaptive functioning development in infants with agenesis of the corpus callosum.
https://pubmed.ncbi.nlm.nih.gov/40169151/

Brain functional connectivity correlates of autism diagnosis and familial liability in 24-month-olds
https://pubmed.ncbi.nlm.nih.gov/40682020/

Brain Morphometry in Infants Later Diagnosed With Autism is Related to Later Language Skills
http://pubmed.ncbi.nlm.nih.gov/40348602/

Functional connectivity between the visual and salience networks and autistic social features at school-age
https://pubmed.ncbi.nlm.nih.gov/40295911/

Evaluating canonical babbling ratios extracted from day-long audio recordings in infants later diagnosed with autism spectrum disorder
https://pubmed.ncbi.nlm.nih.gov/40286507/

Clarifying the developmental association between gesture and later vocabulary for autistic children
https://pubmed.ncbi.nlm.nih.gov/40220629/