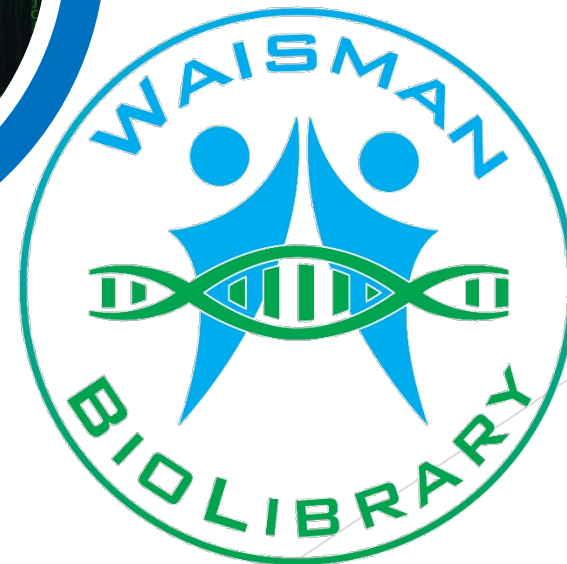


Be INCLUDED: Waisman BioLibrary

How You Can Join the Effort to Advance Knowledge about Down Syndrome



NIH Research Plan on Down Syndrome



- ▶ U.S. Department of Health and Human Services (HHS)
- ▶ First initiated in 2007
- ▶ Understand all aspects of Down syndrome, including related health problems and health outcomes

Research Goals and Objectives



Pathophysiology of Down Syndrome and Disease Progression



Down Syndrome-Related Conditions



Treatment and Management



Down Syndrome and Aging



Research Infrastructure



INCLUDE Project

- ▶ Investigation of Co-occurring Conditions Across the Lifespan to Understand Down Syndrome
- ▶ Improve the health and well-being of individuals with Down syndrome
- ▶ Learn about risk and resilience factors for common diseases that they share with individuals who do not have Down syndrome
 - ❖ Alzheimer's disease/dementia
 - ❖ Autism
 - ❖ Cataracts
 - ❖ Celiac disease
 - ❖ Congenital heart disease
 - ❖ Diabetes
 - ❖ Immune system dysregulation

Waisman BioLibrary: Down Syndrome Study

- ▶ Funded by the NIH INCLUDE Project
- ▶ Creation of biobank, database, and registry
- ▶ Used for comprehensive clinical research and future clinical trials
- ▶ Enrollment of 100 children (ages 0-17 years) with Down syndrome



Who can participate?



Under 18 years old with a diagnosis of Down syndrome

AND



Willing and able to provide a blood or saliva sample

Study Participation



One-time visit to the Waisman Center lasting 2 – 3.5 hours

Parent completes questionnaires on their child's abilities and behaviors



Child with Down syndrome provides a blood or saliva sample



Child may also complete an in-person testing session to assess cognitive ability, memory and learning



Each family receives payment up to \$150, a parking pass, and a round-trip mileage reimbursement



Waisman BioLibrary: Down Syndrome Study



Purpose of blood/saliva collection



Purpose of parent/child assessments

Future Directions

- ▶ Enroll individuals
 - ▶ Of ALL ages
 - ▶ With a diagnosis of intellectual and developmental disabilities, genetic disorders, and/or neurodegenerative diseases



Be included.



Fill out a reply form



Receive an invitation packet (flyer and consent form)



Study team will call you to answer questions and complete eligibility screening



Complete a one-time study visit

No obligation to participate.

Additional research opportunities

- ▶ Visit waisman.wisc.edu for studies currently enrolling

Vowel Diagnostic Treatment in Down Syndrome

The Vocal Tract Development Lab at the Waisman Center, University of Wisconsin-Madison, needs participants with Down syndrome for a pilot research study. We have developed a diagnostic treatment study designed to improve vowel production in ...

Brain Imaging Study for Adults with Down Syndrome

The Waisman Center is seeking adults with Down syndrome, ages 30 and above, for a research study involving an MRI and a PET scan to examine amyloid plaque in the brains of these individuals. Researcher ...

Parenting and Language Learning in Young Children with Down Syndrome

If you have a child with Down syndrome between 2 and 5 years of age, you and your family are invited to participate in a research study conducted by Dr. Audra Sterling at the Waisman ...

- ▶ Join the Waisman Center Research Registry at www.go.wisc.edu/iddregistry
- ▶ Join NIH's DS-Connect at <https://dsconnect.nih.gov/>

Questions?

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<https://www.waisman.wisc.edu/biolibrary>