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
INVESTIGATION OF CO-OCCLUDING 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
- 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](http://www.go.wisc.edu/iddregistry)
Questions?

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