

# ABC-DS and TRC-DS Research Studies

## Co-Enrollment Q&A



### What is ABC-DS?

It's a study of Alzheimer's disease in people with Down syndrome. Over five years, researchers collect health information and blood samples from participants and their siblings to measure changes in the brain. Every 16 months, participants provide information about their physical and mental health so that researchers can track changes in the brain. Participants in the study undergo physical exams, blood draws, brain scans, and other assessments to measure thinking skills, memory, and movement. ABC-DS stands for Alzheimer's Biomarkers Consortium-Down Syndrome and its website is <http://abcds.pitt.edu>.



Trial-Ready Cohort-Down Syndrome

### What is TRC-DS?

It is a study matching people with Down syndrome to clinical trials that are designed to treat or even prevent Alzheimer's disease in people with Down syndrome. Researchers are building a group or cohort of people with Down syndrome to fast-track them into future clinical trials. TRC-DS is pronounced "Track DS" and stands for Trial-Ready Cohort-Down Syndrome. Its website is [www.TRCDs.org](http://www.TRCDs.org).

### Can someone be enrolled in both studies at the same time?

Yes, there are no additional procedures if you decide to co-enroll in TRC-DS. We call participants who enroll in both studies **TRC Stars** (pronounced "Track Stars"). You simply agree to share your data and be contacted in the future if you seem to be someone who would be eligible for a clinical trial. Through this information sharing, **TRC Stars** can make an even bigger difference in Alzheimer's research.

### How can I become a TRC Star?

Please contact your ABC-DS Study Coordinator to discuss and review the "Addendum

Information and Consent Form for Data Sharing and Co-Enrollment with the TRC-DS Study." Once reviewed and understanding is confirmed, a signature is required to indicate informed consent for co-enrollment in both studies. Participation is completely voluntary!

### Are there benefits to being a TRC Star?

Yes! By becoming a **TRC Star**, participants can:

- Help support Alzheimer's research.
- Learn about clinical trials specifically designed for people with Down syndrome when they become available.
- Be fast-tracked to participate in future clinical trials, if eligible.
- Contribute to two studies without extra tests or procedures.

# Co-enrollment of ABC-DS Participants in TRC-DS

Enroll in ABC-DS  
(co-enroll in TRC-DS)

Visit research center every 16 months  
Brain scans | Thinking tests | Blood tests

Become a TRC Star

If you are interested in hearing about future clinical trials, become a TRC Star by signing the co-enrollment consent form to simply share your research data with TRC-DS

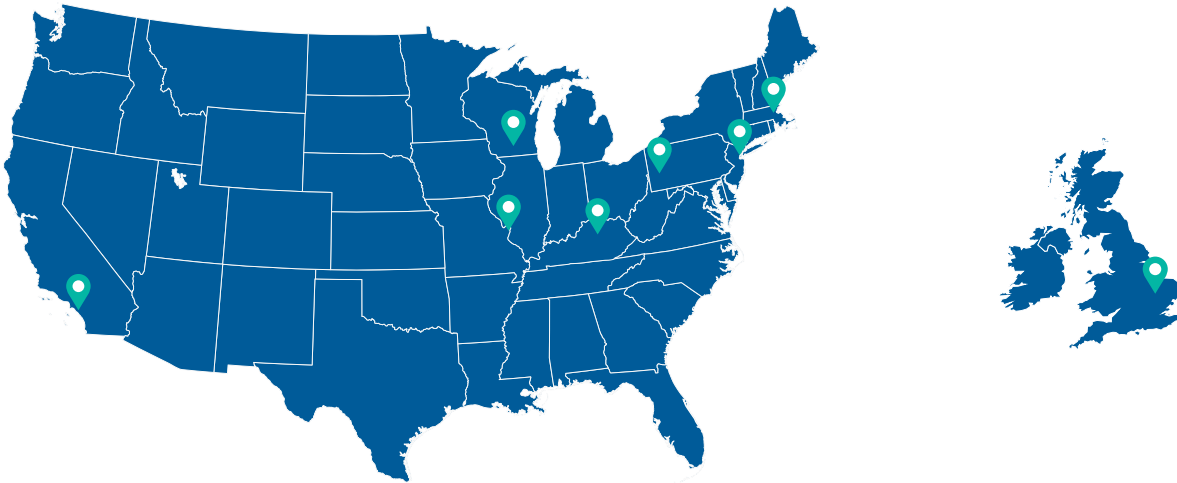
Both ABC-DS and TRC-DS studies are funded by the NIH

ABC-DS = Alzheimer's Biomarker Consortium - Down Syndrome

TRC-DS = Trial Ready Cohort - Down Syndrome

## Where can someone become a TRC Star?

There are currently eight research centers with both studies:



- Harvard Medical School, Massachusetts General Hospital
- New York State Institute for Basic Research/ Columbia University Irving Medical Center
- University of California, Irvine
- University of Cambridge, UK
- University of Kentucky: Sanders-Brown Center on Aging & Kentucky Neuroscience Institute
- University of Pittsburgh
- University of Wisconsin - Madison, Waisman Center
- Washington University in St. Louis Medical Center

## Where can someone learn more?

Visit [TRCDS.org](http://TRCDS.org) or <http://abcds.pitt.edu/> and contact the nearest research center to speak with a staff member who can answer all questions.