

## YOU MAY BE ELIGIBLE

to participate in the LIFE-DSR Study if you meet the following:

- + You, the adult with DS, must have a study partner who has frequent interaction with you on a regular basis.
- + You (or a caregiver who may legally consent for you), in addition to your study partner, must be able to understand and be willing to sign the written consent form.
- + Your study partner must be able to facilitate your participation in the annual clinic visits as required by the study physician or coordinator and provide accurate responses to questions about you, the person with DS.
- + You, the person with Down syndrome, and your study partner must be capable of reliably completing the study requirements.

## PURPOSE OF THIS RESEARCH STUDY

Scientists want to learn more about how adults with Down syndrome (DS) change as they age. They particularly want to develop tools to measure the changes that are associated with Alzheimer's disease for people with Down syndrome.

Scientists experienced in research are conducting the study, along with the LuMind IDSC Foundation.

### FUNDING PARTNERS

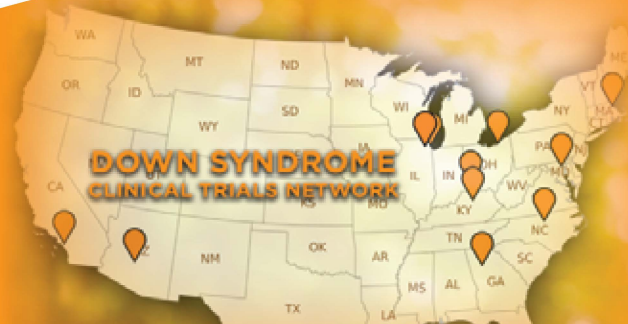


# LIFE DSR STUDY

Longitudinal Investigation  
for Enhancing  
Down Syndrome Research



*\*Not participants in the study.*



To learn more  
visit [ds-ctn.org/LiFE-DSR.html](http://ds-ctn.org/LiFE-DSR.html)

Down Syndrome Clinical Trial Network  
20 Mall Road, Burlington MA 01803  
781-825-1300

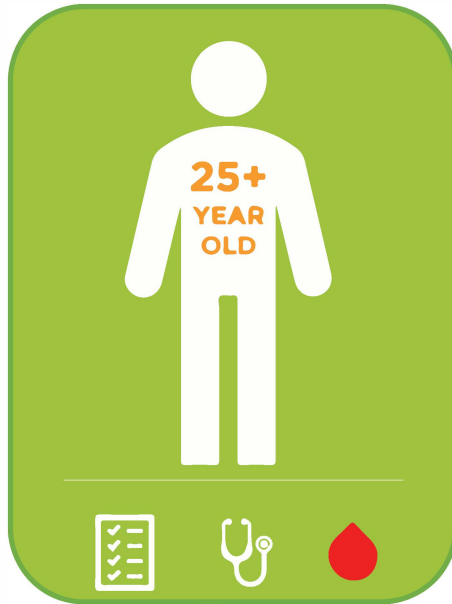


*\*Not participants in the study.*

# FREQUENTLY ASKED QUESTIONS

## ABOUT THE LIFE-DSR STUDY

270 adults with DS over the age of 25 are expected to be in the 2-year study from 2019 - 2021.



### Participants can expect:

1. a standard health examination with a blood draw;
2. tests to evaluate your memory, mood, behavior and ability to perform certain tasks; and
3. 2 follow-up visits – one year and two years after your first visit to repeat the examination, blood draw, and evaluation tests.

### What are my rights if you take part in this research study?

The decision to be in the study is up to you. You can choose to not take part, or you may stop for any reason. You do not lose any of your legal rights by participating in this study.

If you stop taking part in the study, you may request that your data or blood samples be destroyed, but it may not be possible to destroy all of this information if already used for research.

### How will my privacy be protected?

All information about you needed for this study will be kept private, confidential, and secure, including any information sent over the Internet. Data that is collected on you during this study will be kept electronically for the study by the Alzheimer's Disease Cooperative Study (ADCS) based at the University of California at San Diego.

The blood samples will be processed into plasma and will be stored for future research at National Centralized Repository for Alzheimer's Disease and Related Dementias (NCRAD) at the Indiana University School of Medicine. Information about you would only ever be given out without your consent if required by law. If any information from the study is published or presented at scientific meetings, your name and other personal information will not be used. The scientists and study teams doing the study will keep your information private.

### How do I get involved?

To be part of the study, you will need to be evaluated by a doctor who is a LIFE-DSR physician who can determine if you can participate in this research study.

### Will I be compensated for participation?

You will receive compensation for each visit that you complete for this study, as well as reimbursement for the costs of traveling to your study visits.

### Are there risks involved in the LIFE-DSR Study?

All research studies, including the LIFE-DSR Study, may involve some risks associated with participation. There are small risks associated with this Study including the following:

- After the blood draw, some people may faint, have puffiness, bruising, pain or bleeding on their arm.
- The questionnaires used in this study may include personal questions that may make some participants uncomfortable. In addition, answering the same questions every year may be frustrating, boring or tiring. You do not need to answer any questions that you are not comfortable with.
- Even though every effort will be made to protect your privacy, there is a risk of disclosure of your information.