



What is LIFE-DSR?

The Longitudinal Investigation for the Enhancement of Down Syndrome Research (LIFE-DSR) is a multi-year, coordinated research study by medical and academic professionals to track and analyze the medical and physical data of 270 adults with Down syndrome.

Because LIFE-DSR is an “observational and natural history” study, it isn’t testing the impact or effectiveness of a certain medication or therapy. Rather, LIFE-DSR “observes” people as they are by recording medical, physical, and behavioral data points, like: height, weight, blood/plasma samples, key behaviors, sleeping patterns, and blood pressure. Researchers will use the information collected from all study participants, to better understand the clinical profile of people with Down syndrome.

Learning more about the physiology of people with Down syndrome gives researchers better insight into the connection between Down syndrome and Alzheimer’s disease. LIFE-DSR aims to address the questions of why the rate of Down syndrome-related Alzheimer’s disease is so high, and what therapies and treatments can be developed to prevent it.

The people with Down syndrome who take part in LIFE-DSR are known as “participants,” and their caregivers/family members are called “study partners.” All study participants are attached to a specialized clinical “site” located in different cities across the U.S., and develop an ongoing relationship with the clinical team and coordinators at their site through visits every 16 months. Individuals 25 years and older can consider joining the study.



Participating in LIFE-DSR

We welcome new LIFE-DSR participants, and we hope you will consider signing up! LIFE-DSR depends on volunteers from the community who want to help researchers learn more about Down syndrome.

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 participating doctors, and the LuMind IDSC Foundation.

People who choose to participate in the LIFE-DSR study can expect:

- 1** Three or more visits to your clinic site over two years. At the site, you will meet with your team and the study doctor. You will have a physical exam, including a blood draw.
- 2** You will be asked to have a conversation called a “cognitive assessment,” and it will help the researchers measure things that can't be measured with a scale or a tape measure, like memory, language, and the ability to recognize objects.
- 3** Depending on which site you are connected to, you may be asked to participate in additional tests, such as a PET scan of your brain, a collection of spinal fluid, or a discussion of how you can set goals to work on skills or overcome challenges that are important to you.
- 4** You and your study partner will learn about measurements and tests available at the site you are connected to. You will have the opportunity to ask questions before you agree to participate. You and your study partner will “give consent” before you join the study.

For more information, contact us at DSresearch@LuMindIDSC.org.