

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:
 - 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.
 - 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.
 - 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.
 - 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.