



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.