About the LIFE-DSR Expansion and Sub-Studies

The success of the LIFE-DSR study and the Down Syndrome Clinical Trial Network depends on individuals with Down syndrome and their caregivers who make their voices heard, raise their hands, and participate in research.

If you have ever asked: "How can I make a difference?" participation in LIFE-DSR is a great way to help researchers learn more about Down syndrome. New discoveries and breakthroughs in care can – and will - happen, but it will take an ongoing partnership between you, your loved one with Down syndrome, and the dedicated staff who have made Down syndrome medical research a professional priority.

The goal of the LIFE-DSR study is to characterize a real-world adult DS population for future Alzheimer's prevention clinical trials in DS; and this new opportunity to build on industry engagement by way of four sub-studies will significantly expand the scope of research. It will also boost government and industry interest in addressing the Down syndrome community's most concerning challenges.

The LIFE-DSR study is finding novel ways to answer clinical experts' demand for biomarker data in the Down syndrome population with the addition of new sub-studies. These additional biomarker data, correlated with long-term clinical data, will prove vitally important to ensure the DS community has the possibility of enrolling in future trials and ultimately has access to therapeutics, interventions, and medications that are safe and meaningful for people with Down syndrome.

Researchers have already learned some important information from early analysis of plasma biomarker data from the LIFE-DSR study. The biomarker analysis shows evidence of DS-AD progression beginning at approximately 40 years of age, allowing new insight into the clinical profiles specific to DS-AD pathophysiology.

The sub-studies, outlined below, will not be offered at all LIFE-DSR sites. Participating clinics will receive specific protocol training, participant-facing materials, and ongoing support from LuMind IDSC.

	Sub-study activity	**Subjects & Visits**
LIFE-DSR	tau PET tracer scan	30 participants, at least 2 time points
	CSF and blood collection	30 participants, at least 2 time points
	Goal Attainment Scale (GAS) interviews	45 caregivers, 3 time points
	Strydom Composite Assessments	60 participants, 2 time points

Thank you for your consideration. Please reach out to your clinical site coordinator for more information. We look forward to partnering with you!