Happy New Year! Welcome to the LIFE-DSR Study

LIFE-DSR is starting 2020 strong with 70 volunteers enrolled in 7 sites throughout the DS-CTN network. As a parent of a 6-year-old with Down syndrome, I know that enrolling your loved one in a clinical trial is a difficult decision. After decades of working to find treatments for Alzheimer’s, I also know how essential natural history studies are for approved treatments to be effective for special populations.

The LIFE-DSR Study team is motivated to make sure new Alzheimer’s treatments developed for the general population also benefit the 85,500 adults with Down syndrome over the age of 35 in the US today who are at-risk of developing Alzheimer’s. With your enrollment last year, you are giving the gift that keeps on giving. Thank YOU.

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LIFE-DSR Active Sites

The LIFE-DSR Study team is always available to answer your questions. Please visit http://ds-ctn.org/LIFE-DSR-sites.html for contact information.
Meet Dr. William Mobley, LIFE-DSR Project Director

What should volunteers know about LIFE-DSR?
All natural history studies are the foundation to understanding all medical conditions and how they impact people. They inform future trials to help the most vulnerable groups and treat conditions in the most effective way. As a LIFE-DSR volunteer, they have direct access to medical experts who are interested in their well-being. But most importantly, they are pioneers blazing a path toward treatments for Alzheimer’s, and eventually cognition, speech, language, and sleep apnea.

What advice do you have for families and the healthcare providers who care for people with Down syndrome?
I think families who already support their children tremendously can make sure their loved ones eat well, exercise, and be very active socially with friends. They can learn about and watch out for common medical issues in their loved ones and feel empowered to communicate anything that is not normal for their child to their doctor.

Healthcare practitioners should recognize that people with Down syndrome have complex medical stories and feel empowered to reach out to us at DS-CTN for advice and help with any question. Today, only about 2% of adults have a care provider with DS expertise. We can share what we have learned about symptoms that children and adults with Down syndrome experience, which can help them get at the root cause.

Related News About Alzheimer’s
www.DS-CTN.org/alzheimers.html

Biogen to Seek Approval of Aducanumab for Early Alzheimer’s Based on New Analysis of Trials
CareBand Tracking Bracelet Wins NIH Award, May Detect Agitation in Alzheimer’s, Related Dementias
These Essential Supplies Make Caregiving a Little Easier

Health Tips to Lower Your Risk
www.DS-CTN.org/alzheimers.html

Being more socially active in your 50s and 60s predicts a lower risk of developing dementia later on, finds a new UCL-led study.
Can diet and exercise prevent Alzheimer’s disease?
10 Stimulating Activities for Alzheimer’s
15 simple diet tweaks that could cut your Alzheimer’s risk

LIFE-DSR is a study coordinated by the Down Syndrome Clinical Trials Network

DS-CTN Funding Partners

LIFE-DSR Newsflash  www.ds-ctn.org/LiFE-DSR.html