

The Down Syndrome Clinical Trials Network (DS-CTN)

Frequently Asked Questions

What is the goal of the network?

The goal for the DS-CTN is to carry out clinical trials more rapidly with the readiness of clinical sites and the availability of ready-to-enroll participants with Down syndrome. The initial focus will be aimed at preventing Alzheimer's onset in people with Down syndrome as well as support relevant observational studies. As the DS-CTN evolves, we intend to encompass a larger proportion of the Down syndrome population and expand the focus to include readiness for trials involving speech challenges, sleep disturbances, significant behavioral and mental health issues, autism, "Down syndrome Disintegrative Disorder," and auto-immune conditions. Several of the initial DS-CTN clinical sites already see pediatric-aged patients, allowing us to expand the focus of the DS-CTN in future years.

How will DS-CTN speed up the availability of treatment options, and why is this important to families?

Having an organized and coordinated network of sites with an identified cohort of potential participants in clinical trials will allow our community to accelerate future enrollment in clinical trials. We also feel that DS-CTN will attract more industry companies to conduct clinical trials with their promising therapies in people with Down syndrome. Also, the network will allow for consistency across clinical sites that will increase the quality of any trials conducted under best care practices.

What types of clinical trials may be conducted through the DS-CTN network?

We hope to conduct interventional trials (that is, with experimental drugs, devices and other therapeutic modalities such as digital medicines) and observational studies (such as a natural history studies and biomarker studies) through the DS-CTN network.

Do you have an initial focus for the work of DS-CTN?

Our initial focus is on adults with Down syndrome, with a near-term goal of preparing for possible clinical trials aiming to prevent the onset of Alzheimer's disease, with several new clinical trials that could start as early as in 2020.

Where are the initial clinical sites located and do you plan to expand to other clinics?

We awarded grants to the following clinics: Advocate Health (Chicago, IL), Barrow Neurological Institute (Phoenix, AZ), Case Western Reserve University (Cleveland, OH), Cincinnati Children's (Cincinnati, OH), Duke University (Durham, NC), Emory University (Atlanta, GA), Kennedy Krieger Institute/John Hopkins (Baltimore, MD), Massachusetts General Hospital (Boston, MA), UC Irvine (Irvine, CA), Rush University (Chicago, IL) and University of Kentucky (Lexington, KY). Over time, we hope to expand to additional clinical sites and locations.

How can my family member with Down syndrome benefit from the DS-CTN network?

If you are located near the clinics in the cities above, please contact your local clinician to see how you can participate. The initial study is a natural history study that includes an initial visit, with possible follow up visits in following years, where background information, blood, and/or neuropsychological testing may be collected on your child or sibling with Down syndrome. Those families enrolled will be informed about future clinical trials and the possibility of participating.

How can I help support the DS-CTN effort?

You can help support the participation of a clinic near you. Please contact us at ds-ctn@lumindrds.org