

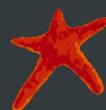


Advance effective treatments for people with Down syndrome.  
 Attract more public and industry sponsors to conduct clinical trials for DS.  
 Significantly and tangibly improve the care of those with DS.



11 sites ready and coordinated to conduct large, multi-site trials in 9 states by 2020 supervised by experienced clinicians who are experts at providing medical care for **children and adults with Down syndrome**. Our first focus is supporting observational studies and preparing for possible clinical trials aimed at preventing Alzheimer's onset in adults with Down syndrome – because promising medicines are ready and 55% of people with DS are at higher risk of symptoms by age 50. Future expansion will include readiness for trials involving speech, sleep, behavioral, and auto-immune conditions in pediatrics and adults.

Funded with support from ...



# 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 DS population and expand the focus to include readiness for trials involving speech, sleep, behavioral, auto-immune conditions, and other 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 group 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 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) and observational studies through the DS-CTN network.

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

Our initial focus is observing the health needs and possible declining cognition in adults with DS. A near-term goal is 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 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 if it is possible to participate. The initial study is a natural history study that includes an initial visit, with follow up visits in following years, where background information, blood, and/or neuropsychological testing will 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](mailto:ds-ctn@lumindrds.org)