



2020 Impact Thanks to Donors Like You



Engaged with our families and friends with stories, support, and resources on social media who responded with **1.1 million likes, comments or shares.**

68,000
Visits to LuMindIDSC.org



68,000 visits to **LuMindIDSC.org** from families, friends, and others that support people with Down syndrome for information about **current research, COVID-19 updates, family weekend events, and other content related to Down syndrome.**



First COVID-19 and Down Syndrome Q&A

Mobilized several Down syndrome organizations and medical experts to publish and regularly update the first COVID-19 and Down Syndrome Q&A that was accessed by over **24,000 families on our website since April.**



4500
Participants

Led **3** surveys, **10** focus groups and **6** webinars with **4500** parents, siblings, and caregivers on critical topics from **COVID-19**, sleep apnea, independence and adult caregivers for Down Syndrome.



Founding supporter to make **DSC2U (Down Syndrome Clinic To You)** available for families caring for loved ones with Down syndrome to get personalized healthcare information developed by experts from **Massachusetts General Hospital and Harvard Medical School.**



Launched myDSC (My Down Syndrome Community), a free online community and growing library of over **250 Down syndrome publications, resources, tools, and discounts** from trusted partners where families or caregivers create a profile to get a dashboard of resources tailored to the age of their loved one and their selected topics.



Increased the voices, experiences, and concerns of families with aging adults with Down syndrome who participated in a series of focus groups in partnership with the **National Down Syndrome Society and Eli Lilly and Company.**

14 sites **2** New Clinical Sites

Expanded DS-CTN (Down Syndrome Clinical Trials Network) to 14 sites in 10 states welcoming 2 new top specialty clinics to give more families access to promising studies and trials.



5 Research Studies & Clinical Trials

Supported 5 research studies and trials with promising intervention, caregiver support tools, and diagnostics for Alzheimer's disease, sleep apnea, and cognition.



5 Studies and Trials in 2020

1

LIFE-DSR

LIFE - DSR - Natural History Study for Down Syndrome

Reached **47% recruitment for LIFE-DSR** (Longitudinal Investigation for the Enhancement of Down Syndrome Research) and forged a new partnership with Eli Lilly and Company (Lilly) highlighted by testing a subset of blood samples with Lilly's novel blood test for Alzheimer's disease.

2



MapHabit - Visual Maps for Independence

Recruiting girls and boys with Down syndrome who are **7 to 17 years old** to test a digital app that aims to increase independence with daily living tasks with visual maps and social stories.

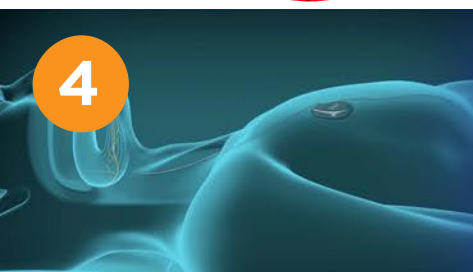
3



GoalNav - Symptom Tracker for Alzheimer's Disease

Recruiting adults with Down syndrome **over the age of 25** and those with a diagnosis of Alzheimer's disease to use a desktop or mobile app that enables caregivers to track Alzheimer's symptoms and create care plans for their loved ones that can also be shared with their healthcare practitioner.

4



Inspire Medical/MEEI - Device for Sleep, Speech, and Cognition

Seeded the funding to expand the **Hypoglossal Stimulation clinical trial** for a Sleep Apnea implant to include speech and cognition which led to a **\$4M grant from the NIH**.

5



Apnimed/Univ. of Arizona - Drugs for Speech, Sleep, & Cognition

Supported expanded data collection for cognition and speech in NIH-supported study of the novel combination drug therapy with atomoxetine and oxybutynin (ato-oxy) to treat sleep apnea.



Recommendations for NIH Research Plan

Led a major collaboration with 50+ top international expert researchers and clinicians to submit recommendations to the NIH for advancing medical research that will dramatically improve the health and well-being of individuals with **Down syndrome by 2030**.