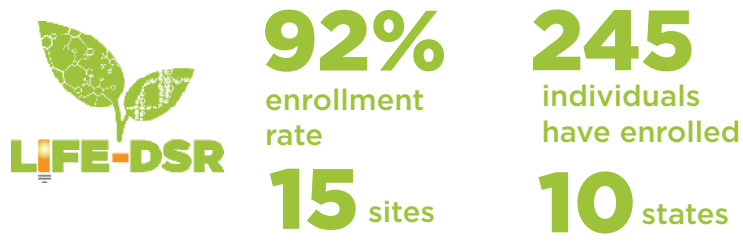




2023 IMPACT REPORT

Down Syndrome Research Progress

- **LuMind IDSC** and pharma **Lilly** partnered on a **multi-year project** to launch Down syndrome-related research and awareness activities. **Lilly** joined Alkermes, Merck, and Abbvie in the **LuMind IDSC Research Consortium**.
- With support from **LuMind IDSC**, researchers at **Mass General Hospital** achieved expanded FDA approval of **Hypoglossal Nerve Stimulation to treat sleep apnea** in people with Down syndrome as young as 13 years old.
- **LuMind IDSC** sponsored, supported, or authored **five peer-reviewed publications** in 2023.



- **Goal Attainment Scale** sub-study completed enrollment. This study is for cognitive assessment.
- **LIFE-DSR-BIO** sub-study was launched to better understand Alzheimer's Disease in Down syndrome. The first milestone was achieved. Five participants attended their initial study visit.

Advocacy For The Community

During 2023, LuMind IDSC emerged as the national leader in identifying - and recommending solutions to - the many barriers preventing people with Down syndrome from accessing newly-developed drug therapies to treat Alzheimer's disease.

- LuMind IDSC leaders met with federal policymakers at the Centers for Medicaid and Medicare (CMS) and the U.S. Food and Drug Administration (FDA) to **outline the complex needs of the Down syndrome community, and how federal policy will impact an entire generation of adults with Down syndrome**.
- Together with the National Task Group on Intellectual Disabilities and Dementia Practices (NTG), LuMind IDSC convened a group of experts to issue a consensus statement **urging public and private payers, including CMS, to modify prescription criteria so that people with Down syndrome and Alzheimer's disease have access to FDA-approved anti-amyloid drugs**.
- An OpEd piece in The Boston Globe and an article on the Reuters network **helped raise public awareness of the urgent need for policy change**.



www.MedEquity4DS.org

LuMind IDSC brought national attention to the barriers that prevent people with Down syndrome from accessing Alzheimer's drugs. A digital petition launched in July to collect signatures and comments from concerned community members, self-advocates, and caregivers.

1000+ signatures on our online petition demanding Down syndrome participation in clinical trials and subsequent access to new Alzheimer's therapies. Here are a few of the 1,000 comments we received on our digital petition site:

“ I have Down syndrome and want the same medical treatment as everyone else. ”

“ My daughter deserves equitable access to pharmaceutical therapies for a disease she has a high risk of developing. ”



Connecting in the Community

As the bridge between the Down syndrome community and Down syndrome research, LuMind IDSC continues to make connections throughout the world with other national organizations, local associations, and research industry leaders to further our mission.

16

Runners

6 ran the Chicago Marathon and 10 ran the New York City Marathon.



20K+

connections made

with the Down syndrome community at 12 in-person events in 12 different states, plus D.C.!



9

research-informed presentations

across the U.S. to professional and family audiences.



Digital Community

Our online community program, myDSC (my Down Syndrome Community), offers free resources to both families and professionals.

4000+

Members in our myDSC online community to support families and individuals with Down syndrome.

260K+

Social Media followers on three platforms and 17 Facebook support groups.

400+

attendees for myDSC webinar series. Topics include Sleep Apnea, Independence, and more. Recordings are available online.

900+

Down syndrome publications, resources, and tools in our online resource library.

Community Support

At LuMind IDSC our mission is to accelerate research to increase the availability of therapeutic, diagnostic, and medical care options and empower families through education, connections, and support. Our mission is possible because of support from the community.



\$287K+

gross funds raised during five annual events: Summer Double Dip, Arts & Blues, Funding Futures Chicago, UnWine(d), and Ashley Rose Golf Tournament.

1,953

total donations this year, including a 31% increase in general contributions and major gifts.

69%

increase in major gifts.

64%

of major donors from 2022 made another gift in 2023.