



IMPACT REPORT 2022

DOWN SYNDROME RESEARCH LEAPS FORWARD IN 2022



- LuMind IDSC was at the forefront of a **surge in interest in Down syndrome research**, and we strategically leveraged it toward the growth of new coalitions, stronger community-facing programs, and the expansion of our Research Consortium.

- **Alkermes** joined Merck and AbbVie in the LuMind IDSC Research Consortium.

- We developed a **first-of-its-kind curriculum and interactive training platform** for the administration of cognitive assessments to people with Down syndrome.

- LuMind IDSC **led the national conversation** around the U.S. CMS reimbursement policy of anti-amyloid drug Aduhelm, and the impact that policy could have on people with Down syndrome.

- Recruitment for LIFE-DSR, our natural history study, reached **80% of our goal, with just 54 participants left to go!**

- The Down Syndrome Clinical Trials Network **launched and completed enrollment** of a Down syndrome-specific study "Goal Attainment Scale," a key component of LIFE-DSR.



5,151

caregivers **responded to a LuMind IDSC-sponsored survey** on COVID-19 vaccines



216

people with DS age 25 and up are **enrolled in LIFE-DSR** at 14 sites across the U.S.



20K+

people **viewed research-related pages on our website** since its relaunch in Sept. 2022



9,000

people **attended a conference-based presentation, lecture, or virtual webinar** hosted by LuMind IDSC



1,728

total donors this year, including a 21% increase in general contributions and major gifts

19 Runners

10 ran the New York City Marathon
7 ran the Chicago Marathon
2 ran the Berlin Marathon

\$250K

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

54%

increase in total donors (not including events)



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4,000

families and professionals accessed our digital resource library - double the number we had last year!

836

vettted resources are currently housed in the myDSC Resource Library

791

registrants attended myDSC webinars where experts discussed a range of topics, from adoption and sleep to results from clinical trials and other research projects

716

families attended - and celebrated! - our **10th** Annual Family Weekend at 19 sites across the U.S.



Resources for Professionals

This year, myDSC added a “Resources for Professionals” section intended to help people working with the Down syndrome community—such as teachers, researchers, and medical professionals—get more information on subjects relevant to them.

Resources added to this section include: studies on the effects of COVID-19 on individuals with Down syndrome, discussions of ableism and how to address it, and information on medical conditions common in people with Down syndrome.



myDSC has members in all 50 states in the United States and it continues to grow, now internationally, counting members in countries such as:

Australia	Nigeria
Canada	Norway
Colombia	Pakistan
Croatia	Portugal
France	Spain
Germany	Sweden
India	Switzerland
Mexico	U.K.

This year, in partnership with six local and national “affiliates,” we proudly launched a Research Awareness Community program, designed for DS organizations to understand, discuss, and find ways to disseminate to their own communities critical information about clinical trials and other scientific initiatives.

