

DOWN SYNDROME RESEARCH LEAPS FORWARD IN 2022



- LuMind IDSC was at the forefront of a **surge in interest in** Down syndrome research, and we programs, and the expansion of our Research Consortium.
- Alkermes joined Merck and
- We developed a first-of-itskind curriculum and interactive training platform for the
- LuMind IDSC led the national conversation around the U.S. CMS reimbursement policy of anti-amyloid drug Aduhelm, and the
- 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



5,151

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



20K+

people viewed researchrelated pages on our website



216

are enrolled in LIFE-DSR at 14 sites across the U.S.



9,000

people attended a conferencebased 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)





4,000

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

836

vetted resources are currently housed in the myDSC Resource Library

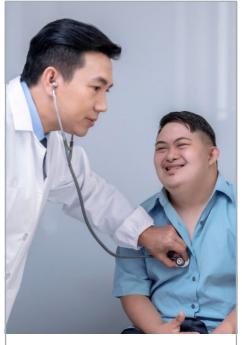
791

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 C
Croatia 💮	Portugal 9
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.

