



2024 IMPACT REPORT



RESEARCH

10,000 datapoints collected & ready for analysis, thanks to LIFE-DSR participants!

In 2024, the Longitudinal Investigation for the Enhancement of Down Syndrome Research (LIFE-DSR) became the **second-largest natural history study** of adults with Down syndrome in the U.S., thanks to the generous participation and enthusiasm of **254 families**.

Over the past five years, **14 research sites** collected more than **10,000 pieces of data** about LIFE-DSR participants, producing an important and meaningful dataset.

With the conclusion of the study in July, the dataset is being prepared for release and biomarker samples are already available for researchers across the globe to access for analysis and to inform future science.



RESEARCH EDUCATION

With support from pharmaceutical company Eli Lilly, LuMind IDSC produced **two custom videos designed to help explain brain imaging procedures** to people with Down syndrome and their families.

In February 2024, the "What to Expect" video series was launched, and audiences first met Samuel, a man with Down syndrome. The videos follow Samuel and his Dad through **each step of the MRI and PET processes**.

To date, the **videos have been viewed hundreds of times** and **four collaborations have been established to license** the videos.



POLICY ADVOCACY

LuMind IDSC and our partners at National Task Group on Alzheimer's and Dementia (The NTG) spent significant time in 2024 addressing the need for policy adaptations, specifically **the development of a common language among clinicians about the progression of Down syndrome-associated Alzheimer's disease (DS-AD) and care management**.

50 international clinicians and researchers completed a comprehensive survey about the clinical stages of DS-AD.

Analysis of the survey data will be presented to a 15-member expert panel, who will discuss the data and reach consensus solutions. A formal publication of the experts' recommendations is planned for 2025.

NEW REPORT

A RAND report, commissioned by LuMind IDSC, the Alliance for Aging Research, BrightFocus Foundation, and the National Down Syndrome Society found that boosting research investment into the health and wellbeing of adults with Down syndrome would improve quality-of-life outcomes, reduce the costs of caregiving, and extend their health and lifespans by five years.

Analysts at the policy thinktank recommended that treatments and solutions for Alzheimer's disease, discovered through additional research, would benefit adults with Down syndrome, as well as their caregivers, both medically and financially.

COMMUNITY ENGAGEMENT

During 2024, the LuMind team participated in **11 national and international conferences**, conventions and events. Exhibitions, presentations, and sponsorships brought new opportunities to connect with self-advocates, caregivers, and researchers.



- **Added 1208 members, for total of 5183 members (increase of 24% YOY)**
- **2269 members are recent users (44% of all members)**
- **1044 resources now included in resource library**



In 2024, LuMind IDSC welcomed a crowd of **4,000 at 20 Great Wolf Lodge waterparks across North America**. Children and adults with Down syndrome, as well as families and friends attended Family Weekend – the largest event of its kind. **Sixteen brave volunteers** coordinated activities in **12 states and Ontario**, Canada

DONORS & SUPPORTERS

24 dedicated & outstanding volunteers raised funds for our mission via three marathons: New York City, Chicago, and Berlin



Keeping the fun in fundraising, **\$281K was collected during three volunteer-led events:** Funding Futures Chicago, Summer Double Dip, and Arts and Blues.

This year, our operating revenue was \$4.9M, the largest in LuMind IDSC history. Overall, philanthropic revenue saw a **28% increase** from donations received last year:

- 1,877 Donors, **27% increase** from 2023
- 2,449 Donations, **25% increase** from 2023
- **27% Increase** in major gifts from 2023
- **75% of major donors** from 2023 made a major gift in 2024