



**PUSHING FOR CHANGE
TO CREATE A MORE EQUITABLE FUTURE**

2023 Annual Report

Our Mission

Accelerate research to increase the availability of therapeutic, diagnostic, and medical care options and empower families through education, connections, and support.

Dear Friends:

I'm encouraged to report we are making progress on our vision of a world where every person with Down syndrome thrives with improved health, independence, and opportunities to reach their fullest potential. In 2023, LuMind IDSC Foundation focused on three key areas: Advocacy, Education, and Research. Our push for change in each of these areas is driven by our mission to create a more equitable future for the Down syndrome community.

Over the last year we've devoted significant time and energy to bringing attention to the barriers surrounding clinical trials for new Alzheimer's drugs, educating the community on current challenges in regards to obtaining these drugs, and we also continued a multi-year research study to provide valuable data to continue making progress on medical treatments needed within the Down syndrome community.

None of the advances made in 2023 would have been possible without the support of our donors, colleagues, and friends throughout the Down syndrome community. Thank you for partnering with us in the push for change to create a brighter future.



Hampus Hillerstrom
President/CEO LuMind IDSC Foundation



“We are making progress on our vision of a world where every person with Down syndrome thrives with improved health, independence, and opportunities to reach their fullest potential.”

**-Hampus Hillerstrom,
President and CEO**

Advocacy

Alzheimer's disease continues to be a black cloud plaguing the Down syndrome community. But hope arrived this past year with the approval of a new anti-amyloid drug (Leqembi) and more interest from researchers on Down syndrome and Alzheimer's disease. While pharma companies and researchers do their part, LuMind IDSC works on multiple levels to break down barriers and ensure that people with Down syndrome have equal access to emerging Alzheimer's treatments with (or near) FDA approval.

LuMind IDSC Partners with Experts to Ensure Equal Eligibility Criteria

In 2022 and 2023, LuMind IDSC partnered with the National Task Group on Intellectual Disabilities and Dementia Practices (NTG) to lead a consensus panel of 20 experts from the fields of medicine, Down syndrome, and Alzheimer's disease. The group of experts called for drug formulary committees to modify prescriptions criteria to account for the younger onset age of dementia among people with Down syndrome, the use of alternative language in the criteria, and the need for adaptation of assessment instruments validated for cognitive decline in the Down syndrome population.

LuMind IDSC and Lilly Partner on a Multi-Year Project

In another effort to remove barriers to full inclusion in clinical trials and therapies, LuMind IDSC entered into a multi-year project of three key community-based initiatives to increase the knowledge of and interest in research among people with Down syndrome and their caregivers.

LuMind IDSC provided Lilly with policy, cultural, and medical expertise specific to the Down syndrome community's struggles with Alzheimer's disease by:

- Advising them on clinical trial considerations in Down syndrome;
- Creating a comprehensive awareness program to increase the number of people with Down syndrome who are informed of and willing to participate in clinical trials;
- Producing educational videos featuring people with Down syndrome participating in brain imaging scans (MRI, PET) so that others in the community can easily understand, consent to, and prepare for diagnostic brain scans in future research participation.



LuMind IDSC at the 2023 NDSS National Conference in Orlando, Florida

Featured in the News

LuMind IDSC is committed to ensuring the Down syndrome community is keenly aware of the inequity of access to life-changing therapies. As such, we work to educate caregivers and self-advocates on the steps they can take to help rectify the injustice. Mainstream and biotech publications have been devoting space to this important conversation and in 2023 we were excited for features in two important publications.



REUTERS

The
Boston
Globe

What to Expect: Video Series



LuMind IDSC is dedicated to providing individuals with Down syndrome and their families with the tools and information they need to thrive. In 2023, we began work on a video series entitled, “What to Expect: Video Series” to educate individuals with Down syndrome on the process of getting an MRI or a PET Scan. They were released in early 2024.

Research



LIFE-DSR Study

Important work continued in collecting data on people with Down syndrome through the LIFE-DSR study. This multi-year natural history study was designed to generate a deeper understanding of Alzheimer's Disease progression in Down syndrome. Data collected includes an individual's medical history, blood samples, and neuropsychological testing data.

Goal Attainment Scale Sub-Study

The Goal Attainment Scale sub-study met its recruitment goal of 45 participants. We expect to conclude the study in February 2024. The Goal Attainment Sub-study utilizes a dementia-specific menu that is tailored to people with Down syndrome. With this tool, self-advocates, caregivers, along with their physicians, determine from the symptom menu what they want to track over time to see if there is any decline.

LIFE-DSR BIO Sub-Study

LIFE DSR BIO, is a biomarkers sub-study of 30 participants that includes brain imaging, blood, and cerebral spinal fluid (CSF) biomarkers. LIFE-DSR BIO was launched in June 2023.

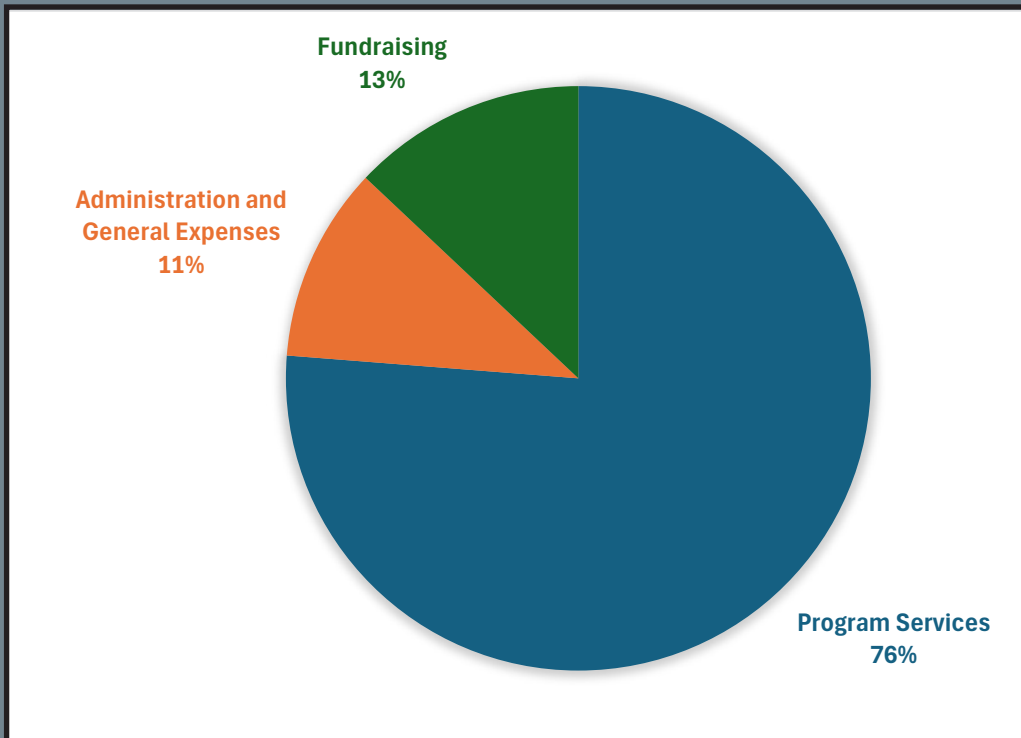
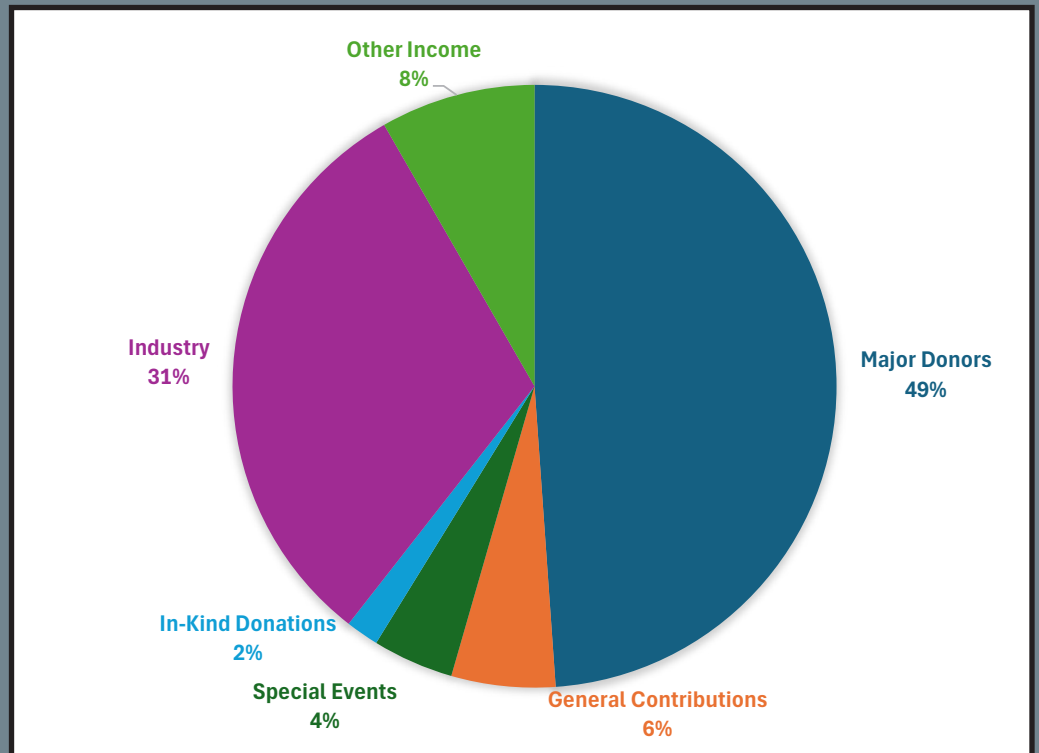


LuMind IDSC at the Massachusetts Down Syndrome Congress (MDSC) Buddy Walk

Financials

\$4,364,518

Public Support & Revenue



\$4,056,823

Expenses

In the Community



2023 Summer Double Dip in the Hamptons, NY



NDSS New York City Buddy Walk



2023 Ashley Rose Golf Tournament in Virginia



2023 Down Syndrome Association of the Valley Buddy Walk in Ohio



2023 New York City Marathon Team

Leadership

President & CEO

Hampus Hillerstrom

Operations

Senior Operations Manager
Loriann Ostiguy

Research

Chief Scientific Officer
Richard Fisher, PhD

Vice President, Clinical Operations
Lois Kelly

Clinical Operations Consultant
Dave Cook

Clinical Project Manager, Clinical Operations
Aisha Vanderhorst

Senior Project Manager, Clinical Operations
Tashia Harris

Clinical Trial Research Associate
Jacki Fung

Clinical Trial Monitor
Jill MacDougall

Senior Manager, Strategy & Research
Amit Das

Development

Chief Development Officer
Michelle Petronio

Senior Director of Philanthropy
Anthony Padgett

Senior Development Officer
Allison O'Hara

Donor Relations & Systems Manager
Janice Fontaine

Marketing & Community Engagement

Vice President, Marketing & Community Engagement
Kate O'Neill

Director of Community Programs
Christina Reaves

Marketing & Communications Manager
Shannon Bergstresser

Marketing Coordinator
Lizzy Luther-Kurtis

Director of Family Programming
Michelle Slape

Social Media & Awareness Coordinator
Jo Zhou

Community Data Coordinator
KIm Warren

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110 Winn Street - Suite 105
Woburn, MA 01801
781-825-1300

LuMindIDSC@LuMindIDSC.org