



Annual Report 2021

Letter from the President & CEO

Like many parents, I have two full-time jobs: “Dad,” and my professional career. I am the proud father of 7-year-old Oskar, who has Down syndrome. He lights up every room, is starting to read, and loves puzzles, hugs, and ice cream. Oskar and his younger brother, Sebastian, are a dynamic duo perfecting the best kind of brotherly mischief, who keep my wife and I fully employed at every hour of the day.

As the CEO of LuMind IDSC, I live at the intersection of family life, non-profit work, and daily adventures with Down syndrome, as do many of my colleagues. Your family, our families, and our experiences inspire us to work to make the future better for people with Down syndrome. Thank you for being part of the LuMind IDSC community.

Every day, LuMind IDSC works at the crossroads of science and the Down syndrome community by focusing on translational research – the kind that focuses on unmet needs and turns successful laboratory and data discoveries into clinical best practices and new treatment options at local doctors’ offices.

Individuals with Down syndrome, their caregivers, and loved ones are at the core of all the activities at LuMind IDSC. We directly serve the community by offering a wide range of multimedia health, wellness, parenting, and support resources on our free digital library platform, myDSC. We also provide the means for families to be heard in research matters by soliciting input from them and bringing that “family voice” to researchers, pharmaceutical companies, and policymakers.

LuMind IDSC is leading the way in accelerating the science and solutions that will enable our loved ones to live longer, healthier, and more independent lives. Thank you, so much, for your support of and participation in our mission. We’re very proud to be moving forward with you and the Down syndrome community.

Sincerely,



Hampus Hillerstrom
President/CEO
LuMind IDSC Foundation



Our Team, FY2021

Hampus Hillerstrom — *President & CEO*

Research

Jim Hendrix — *Chief Scientific Officer*

Angela Britton — *Vice President, Clinical Operations*

Aisha Vanderhorst — *Assistant Clinical Project Manager in Research*

Community Engagement

Beth Sullivan — *Senior Director of Community Engagement*

Michelle Slape — *Director of Family Programming*

Kim Warren — *Community Programs Manager*

Development

Michelle Petronio — *Chief Development Officer*

Rebecca Harris — *Development Manager*

Sasha Fisher — *Events and Online Fundraising Coordinator*

Marketing

Kate O'Neill — *Senior Director of Marketing*

Marly Chevrette — *Director of Marketing*

Elizabeth Luther-Kurtis — *Marketing Coordinator*

Jo Zhou — *Social Media & Awareness Coordinator*

Operations/IT/Finance

Katherine Connell — *Chief Operating Officer*

Loriann Ostiguy — *General Manager & Executive Assistant in Operations*

Michael Lee — *Director of Finance*

Board of Directors, FY2021

Michael Mannor, Ph.D — *University of Notre Dame, College of Business*

Tony Hung — *Pulsar Bio*

Patrick Kannan

Paul Murasko — *Ipsen Biopharmaceuticals*

Maria Dellapina — *Specs4US*

Hector Guinness — *HG Capital*

Christopher Lis, Ph.D. — *ChenMed, Leavitt Partners*

Sohail Masood, Pharm.D. — *Kaba Fusion, owner of Omar's World of Comics*

Claudia Moreira, Ph.D — *Alana Foundation*

Beverly Paperiello — *Heartwood Biopharma Group*

Anthony Providenti — *Heska*

Jeff Strobel — *United States government*

Accelerating Research

For LuMind IDSC, accelerating research—the first goal identified in our mission statement—can take many forms, such as facilitating and funding studies done in partnership with other organizations, and advocating for policy changes to increase Down syndrome representation in research. In fiscal year 2021, we had major accomplishments in both of these areas.

First, we were proud to launch the multi-million-dollar, first-of-its-kind LuMind IDSC Research Consortium with founding pharmaceutical collaborators AbbVie and Merck. The Consortium is the first step in bridging academia, industry, and experts to build a structured and focused translational approach to Down syndrome-related research. The Consortium will bring critical funding to high-impact research projects that will not only bring much-needed results on an individual study basis, but will also inform and improve the research community's knowledge of Down syndrome for further studies.



On that point, the Consortium has already committed support to the Longitudinal Investigation for the Enhancement of Down Syndrome Research (LIFE-DSR) natural history study, enabling LuMind IDSC to initiate several sub-studies in the ongoing cohort. LIFE-DSR—a coordinated research study by medical and academic professionals to track and analyze the medical and physical data of 270 adults with Down syndrome—will now be able to complete additional biomarker research, including a tau PET imaging sub-study and the expansion of fluid biomarker research to include cerebrospinal fluid and plasma biomarkers, thanks to the Consortium. By the end of FY2021, LIFE-DSR had 170 individuals enrolled across 14 Down Syndrome Clinical Trial Network (DS-CTN) sites—up from 12 in FY2020—in 10 U.S. states. In addition, the first data conclusions from the LIFE-DSR study have been published, so it is already providing valuable new information on DS to the scientific community.

This year, we also progressed on other research efforts. Work from prior research grants to Dr. Hiruy Meharana at MIT identified the senescence pathway in Down syndrome. We also completed the MapHabit digital health treatment study for independence with 50 participants, which led to a renewed focus by that company on DS and intellectual and developmental disabilities.

In the policy arena, LuMind IDSC led a Critical Path Innovation Meeting (CPIM) with the U.S. Food & Drug Administration (FDA) to help identify and begin to remove some of the barriers to clinical trials in Down syndrome associated Alzheimer's Disease (DS-AD). In the end, this effort proved we are standing on the cutting edge of Alzheimer's science, and helped the FDA recognize there is a great opportunity to bridge drugs between Down syndrome and the general AD population given the very similar course of disease.

Dignity Health, Barrow Neurological Institute	U. of Kentucky Research Foundation
U. of California, Irvine	Mass. General Hospital
U. of California, San Diego Health	Mass. General Hospital, McLean Hospital
Emory U.	Hugo W. Moser Research Institute, Kennedy Krieger Inc
Advocate Health and Hospitals	Duke U.
Rush U. Medical Center & Children's Hospital	Cincinnati Children's Hospital
U. of Kansas Medical Center Research Institute	Case Western Reserve U.

LuMind IDSC also facilitated the Down syndrome community conversation after the approval of Biogen's Aduhelm—the first new Alzheimer's drug approved since 2003, and the first to attack what is believed to be one of the causes of Alzheimer's disease. We issued several statements and blogposts, and hosted a webinar as a means of sharing accurate information. At this stage, we do not know if the drug is safe or effective for people with DS, but we are actively involved in seeking safety studies with this class of Alzheimer's therapies, and advocating for DS inclusion in that discussion wherever and whenever possible through advocacy efforts with CMS, NAPA Council, NIH, and states together with partners NDSS, NTG, and other national organizations.

Community Engagement



In 2021, our free, online community resource grew to...

1640 members in
44 states

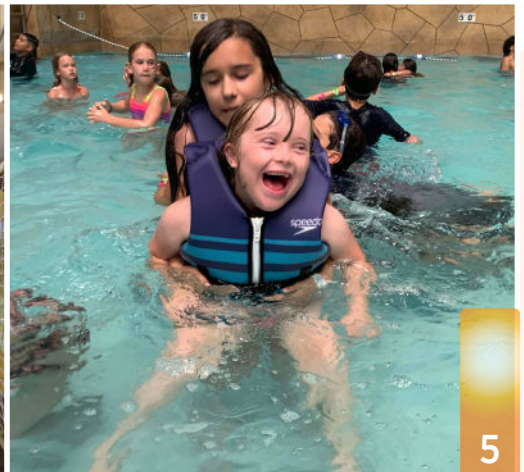
With access to a digital library of more than **700** Down syndrome publications, resources, tools, and discounts.

myDSC, LuMind IDSC's free digital platform for reliable Down syndrome resources and tools, has hundreds of resources, customized libraries of information, and special member discounts with external vendors. This membership portal helps us empower families through education and support—a key part of our mission! In 2021, we grew the platform significantly, bringing the member total to 1,640 and the resource total to 700, helping our community learn about topics as diverse and varied as Alzheimer's disease, adoption, physical activity, and kidney function through webinars, podcasts, guides and more.

In addition, the Community Engagement team helped collect data for two surveys: one on COVID-19 involving 5,151 participants and multiple key publications, showing an increased risk of death in the adult population and the safety and protective effect of COVID vaccines; and another from Boston University on 500 caregivers of adults with DS.

In addition, LuMind IDSC's Community Engagement team was excited to return to an in-person format for Family Weekend in 2021, albeit with some necessary changes to ensure safety and wellness. This annual event, held at 18 Great Wolf Lodge locations across the U.S. and Canada in 2021, brings families in the Down syndrome community together to meet new friends, ask questions and just be themselves in a safe and fun environment.

This year, we brought together 2,500 children, teens, parents, siblings, caregivers, and friends at Family Weekend. Every family who joined us also became members of myDSC, giving them free access to hundreds of educational materials—a perfect companion to the in-person connections and support they made while at Great Wolf Lodge. We know 2022 is going to be even bigger and better!



Raising Research Awareness

In order to accelerate research and meet the unmet medical needs of people with Down syndrome, LuMind IDSC is committed to sharing information that highlights the seriousness of the problems people with Down syndrome face—such as an extremely high rate of Alzheimer’s disease compared to the general population—and the critical importance of research in solving those problems.

In 2021, to begin driving this knowledge, we launched a research awareness campaign titled “myDSmoment,” inviting the community to learn more about Down syndrome research, the steps involved, and how their voices can be amplified. More than 265,000 people engaged with the campaign in fiscal year 2021, and we will continue to push research awareness in the community in 2022 and beyond.

Other significant inroads were achieved in research awareness through media sources and events outside LuMind IDSC’s own channels. President and CEO Hampus Hillerstrom published an article entitled “One More Fight for the Down Syndrome Community” in Exceptional Parent Magazine, which brought the language and information of the myDSmoment campaign to all of that publication’s subscribers.

In addition, we attended the following events and delivered information on research—and how the community, and staff/leadership at other Down syndrome organizations, can get involved:

- Down Syndrome Affiliates in Action Annual Leadership Conference
- Massachusetts Down Syndrome Congress Annual Conference
- Global Down Syndrome Forum
- National Down Syndrome Society Adult Summit
- National Down Syndrome Congress Annual Convention
- Alzheimer’s Association International Conference
- Trisomy 21 Research Society International Conference
- Clinical Trials on Alzheimer’s Disease (CTAD) Congress

1 **#TheyDidI CanWeWill**



Life expectancy for adults with Down syndrome has increased from age 25 in the 1980s to age 65+ today. But many middle-aged and elderly adults with Down syndrome acquire Alzheimer’s disease (AD), at a much higher rate than the general population.

A healthy, independent future for people with DS? #TheyDidI CanWeWill reach it through research.

LuMind IDSC **myDSmoment** lumindidsc.org/mydsmoment

2



David Egan | Athlete, Professional Advocate, and Author of “More Alike Than Different”

myDSmoment **#TheyDidI CanWeWill**

3



A biomarker is a biological marker to measure r
It is a reliable predictor and indicator of dir
and disease progression.

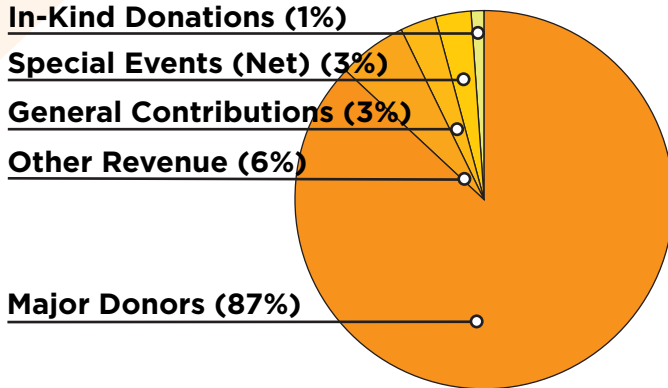
LuMind IDSC **RESEARCH GLOSSARY**
lumindidsc.org/research-glossary

myDSmoment #TheyDidI CanWeWill

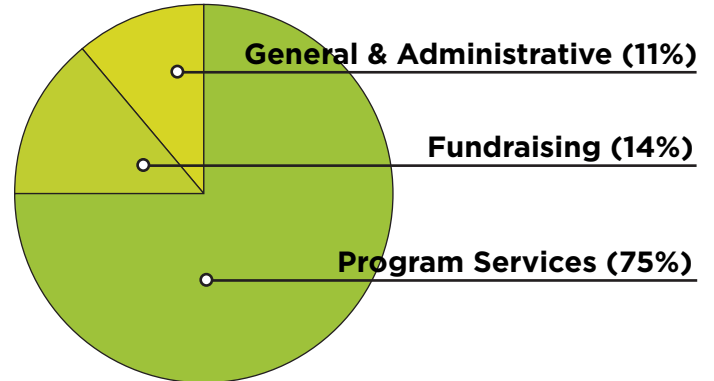
Components of our myDSmoment research awareness campaign:

- 1) social media posts;
- 2) testimonial videos from community members;
- 3) educational materials, including Research Glossary videos & PDF

Financials FY21 (10/1/20 - 9/30/21)



2021 Revenue
\$5,309,485



2021 Expenses
\$3,415,195

FUNDRAISING REVENUE	
Major donors	
Grassroots and general contributions	
Donated services	
Special events revenue	
OTHER REVENUE	
Government conditional grant (PPP)	
Investment income	
Other income	
RECLASSIFICATION OF NET ASSETS	
Net assets released from restriction	
TOTAL REVENUE	
TOTAL REVENUE (FY)	

2021	
Unrestricted	Restricted
\$ 1,295,932	\$ 3,305,450
\$ 186,952	
\$ 42,270	
\$ 153,307	
	\$ 324,071
\$ 1,503	
\$ 2,445,054	\$ (2,445,054)
\$ 4,125,018	\$ 1,184,467
\$5,309,485	

2020	
Unrestricted	Restricted
\$ 966,013	\$ 25,000
\$ 370,801	
\$ 216,131	
\$ 258,541	
\$ 1,301	
\$ 26,044	
\$ 696,000	\$ (696,000)
\$ 2,534,831	\$ (671,000)
\$1,863,831	

EXPENSES by COST CENTER	
Program Services	
General & Administration	
Fundraising	
TOTAL EXPENSES (FY)	

2021	
\$ 2,584,376	
\$ 360,178	
\$ 470,641	
\$3,415,195	

2020	
\$ 1,926,934	
\$ 222,542	
\$ 421,316	
\$2,570,792	



LuMindIDSC.org

20 Mall Road, Suite 200
Burlington, MA 01803-4126