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
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.

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.
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

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

### General & Administrative (11%)

### Fundraising (14%)

### Program Services (75%)

### In-Kind Donations (1%)

### Special Events (Net) (3%)

### General Contributions (3%)

### Other Revenue (6%)

### Major Donors (87%)

### 2021 Revenue Breakdown:
- **Unrestricted:** $4,125,018
- **Restricted:** $1,184,467

### 2021 Expenses Breakdown:
- **Total Expenses:** $3,415,195
- **Program Services:** $2,584,376
- **General & Administration:** $360,178
- **Fundraising:** $470,641

### Fundraising Revenue
- Major donors: $1,295,932
- Grassroots and general contributions: $186,952
- Donated services: $153,307
- Special events revenue: $153,307

### Other Revenue
- Government conditional grant (PPP): $324,071
- Investment income: $1,301
- Other income: $26,044

### Reclassification of Net Assets
- Net assets released from restriction: $2,445,054

### Total Revenue
- **Total Revenue (FY):** $5,309,485

### Total Expenses (FY)
- **Total Expenses (FY):** $3,415,195

---

**FUNDRAISING REVENUE**

<table>
<thead>
<tr>
<th>Source</th>
<th>Unrestricted</th>
<th>Restricted</th>
</tr>
</thead>
<tbody>
<tr>
<td>Major donors</td>
<td>$1,295,932</td>
<td>$3,305,450</td>
</tr>
<tr>
<td>Grassroots and general contributions</td>
<td>$186,952</td>
<td>$370,801</td>
</tr>
<tr>
<td>Donated services</td>
<td>$42,270</td>
<td>$216,131</td>
</tr>
<tr>
<td>Special events revenue</td>
<td>$153,307</td>
<td>$258,541</td>
</tr>
</tbody>
</table>

**OTHER REVENUE**

<table>
<thead>
<tr>
<th>Source</th>
<th>Unrestricted</th>
<th>Restricted</th>
</tr>
</thead>
<tbody>
<tr>
<td>Government conditional grant (PPP)</td>
<td>$324,071</td>
<td>$1,301</td>
</tr>
<tr>
<td>Investment income</td>
<td>$1,503</td>
<td>$26,044</td>
</tr>
</tbody>
</table>

**RECLASSIFICATION OF NET ASSETS**

<table>
<thead>
<tr>
<th>Source</th>
<th>Unrestricted</th>
<th>Restricted</th>
</tr>
</thead>
<tbody>
<tr>
<td>Net assets released from restriction</td>
<td>$2,445,054</td>
<td>$(2,445,054)</td>
</tr>
</tbody>
</table>

**TOTAL REVENUE**

- **Total Revenue (FY):** $5,309,485

**EXPENSES by COST CENTER**

<table>
<thead>
<tr>
<th>Cost Center</th>
<th>2021</th>
<th>2020</th>
</tr>
</thead>
<tbody>
<tr>
<td>Program Services</td>
<td>$2,584,376</td>
<td>$1,926,934</td>
</tr>
<tr>
<td>General &amp; Administration</td>
<td>$360,178</td>
<td>$222,542</td>
</tr>
<tr>
<td>Fundraising</td>
<td>$470,641</td>
<td>$421,316</td>
</tr>
</tbody>
</table>

**TOTAL EXPENSES (FY)**

- **Total Expenses (FY):** $3,415,195

- **Total Expenses (FY):** $2,570,792