

# RELIABLE DOWN SYNDROME RESOURCES FOR EVERY FAMILY, FOR EVERY STAGE OF LIFE

BY HAMPUS HILLERSTROM



*It's no secret that parenthood is a state of constant improvisation. We're all adapting, adjusting, figuring things out on the fly, every day (every hour!). There are many times when we just... guess... and then hope we guessed correctly. No matter how much we prepare, our kids surprise us, and we are forced to re-invent the plan.*

I like plans. I like knowing my options. I'm a data lover, am always looking for the latest research, and usually approach issues armed with information. As the parent of an 8 year old with Down syndrome, I couldn't always find reliable resources when I needed them; and by the time I found what I needed, we were already on

to the next problem – that's how quickly life changes in an exceptional family. I used to be consistently frustrated by the lack of easily accessible, centralized information available for people with Down syndrome and their families.

Thankfully, I lead LuMind IDSC, a national Down syndrome organization dedicated to providing families with reliable resources and responsive research. Our organization launched a one-of-a-kind program called myDSC (my Down Syndrome Community) to help families access good information in an easy way. As the centerpiece of a large constellation of information, resources, and community connections myDSC provides all for free, to families like mine, who are daily navigating the world of Down syndrome.

myDSC is a digital platform for verified Down syndrome resources and tools. It is a free membership portal with more than 700 curated resources, customized libraries of information, and special member discounts with external vendors. Designed by

Down syndrome advocates and caregivers, myDSC provides “one-stop shopping” for families, educators, caregivers, and others seeking evidence-based information on a wide variety of Down syndrome-related topics.

Because of LuMind IDSC’s deep expertise in research and our network of clinicians and researchers, we are able to vet the quality of research and medical resources we provide in myDSC. Through the Down syndrome Clinical Trials Network and the LuMind IDSC Down syndrome Research Consortium, we accelerate translational research into the unmet medical needs of people with Down syndrome and welcome families to learn more about Down syndrome research.

Down syndrome research is of huge importance to our community. As people with Down syndrome live longer and more independently than any generation before, we aim to support their health and wellbeing at every stage of life. Our organization does that through a variety of research initiatives, and by providing family-friendly information and ways to connect.

**For families interested in Down syndrome research:**

- What is Down syndrome research?: <http://www.lumindidsc.org/myDSmoment>
- Down Syndrome Clinical Trials Network (DS-CTN): [www.ds-ctn.org](http://www.ds-ctn.org)
- Introduction to Down syndrome-related Alzheimer’s disease: [www.lumindidsc.org/research](http://www.lumindidsc.org/research)
- Clinical Trial Finder (linked to U.S. government directory): [www.lumindidsc.org/ClinicalTrialFinder](http://www.lumindidsc.org/ClinicalTrialFinder)

**For caregivers looking for medical and health resources:**

- Comprehensive information regarding COVID-19 and Down syndrome: [www.LuMindIDSC.org/COVID19](http://www.LuMindIDSC.org/COVID19)
- Specialized questions and practical answers for adolescent and adult Down syndrome-related health issues: Ask Dr. Chicoine (via free myDSC subscription): [www.myDSC.org](http://www.myDSC.org)
- Down Syndrome Clinic to You (DSC2U) – An online toolkit

**ANOTHER LOOK : MORE DOWN SYNDROME RESOURCES**

In addition to our own curated resources, LuMind IDSC works closely with and highly recommends other Down syndrome organizations with expertise in the following areas.



**NATIONAL DOWN SYNDROME SOCIETY**

Advocacy and employment  
[www2.www.ndss.org](http://www2.www.ndss.org)



**GIGI'S AT HOME**

Virtual programs and services  
<https://gigisplayhouse.org/gigisathome>



**MASSACHUSETTS DOWN SYNDROME CONGRESS**

Pre-natal/newborn resources  
[www.MDSC.org](http://www.MDSC.org)



**YOUR NEXT STAR**

Education and employment initiatives  
<https://yournextstar.com>



**T21RS**

COVID-19 research and resources  
[www.t21rs.org/covid-19](http://www.t21rs.org/covid-19)

**SOCIAL STUDIES : PEER-TO-PEER SUPPORT FOR A WIDE VARIETY OF PEOPLE WITH TIES TO DOWN SYNDROME**

**Facebook Group**

**Audience/Users** [www.lumindidsc.org/s/1914/20/interior.aspx?sid=1914&gid=2&pgid=555](http://www.lumindidsc.org/s/1914/20/interior.aspx?sid=1914&gid=2&pgid=555)

Adoptive Family Support

Support group for parents who have adopted, or are in the process of adopting a child with Down syndrome

Babies and Toddlers

Support group to connect parents who are new to the Down syndrome journey

Connections

Support group for parents and caregivers of loved ones of all ages with Down syndrome

Conexion en Espanol

Conectar a la gente de habla hispana que tienen hijos con Síndrome Down

Dads

Support group for fathers of children with Down syndrome or those expecting a child with Down syndrome

Dual Diagnosis

Support group for parents who have a loved one with a dual diagnosis of Down syndrome and autism

Educators

Support group for certified teachers and teacher assistants educating students who have Down syndrome

Friends and Family

Support group for anyone who has friends with Down syndrome or a loved one with Down syndrome

Grandparents

Support group for grandparents that have a grandchild with Down syndrome

Love and Loss

Support group for people who have lost a loved one with Down syndrome

Parents/Caregivers of

Support group for parents and caregivers of loved ones with Down syndrome that are preteen age

Preteens/Teens/Adults:

through adulthood

Pre-K/Elementary

Support group for parents who have a child with Down syndrome attending pre-K through elementary school

Prenatal Diagnosis

Support group to connect parents who are new to the Down syndrome journey

Research & Medical Care Group

Support group for parents, families, and caregivers

Self-Advocates

Support group to connect people with Down syndrome

Siblings

Support group for siblings of people with Down syndrome

## INFORMATION IS POWER : USEFUL RESOURCES IN THE MYDSC RESOURCE LIBRARY

Useful info for all ages & stages of life		Specialized resources for self-advocates and caregivers of:			
General Medical Health & Wellbeing	Research Info and Opportunities	Infants & Toddlers	School Age Kids	Young Adults	Older Adults
Ask Dr. Chicoine	Clinical Trial Finder	Resources at first diagnosis	Speech assessments	Employment and job training	Regression or Dementia?
Wellness webinars	Research Glossary	Breastfeeding Guide	What is Occupational Therapy?	Physical activity	Alzheimer's disease
DSC2U digital tool	Studies & Surveys	Early intervention services	Your First IEP Meeting	Relationships	Aging in Place
Articles, tip sheets related to specific issues & concerns	Clinical Trial Network	Toilet training	Sibling support	Exploring higher education	Sibling Caretakers
Navigating a doctor's appointment	Sleep Apnea Studies	Resources for grandparents	Gift-giving guides	Independent living	Ophthalmology and Audiology

providing customized, expert-created medical information for families who don't have access to a local Down syndrome clinic: [www.LuMindIDSC.org/DSC2U](http://www.LuMindIDSC.org/DSC2U)

- **Topic-specific webinars on:** Regression, Healthy Eating, Aging, Sleep Apnea, Hearing Loss, ADHD and more (via free myDSC subscription): [www.myDSC.org](http://www.myDSC.org)
- **Información en español (Spanish language resources):** [www.LuMindIDSC.org](http://www.LuMindIDSC.org) → News

### RESEARCH AND ADVOCACY : A MOM'S APPROACH

*"As a parent, research was one of the most important things I leaned on to help me understand more on how I could help our daughter Kate. The day that she was born, and we received her birth diagnosis, one of the first things I looked up was current research being done on Down syndrome. I wanted to be able to use this information to share with providers in helping us to make informed decisions about Kate's future."*

– Nicole White, Ph.D., a mom & research advocate



**ALWAYS LEARNING:**  
Nicole White with daughter Kate

### For families looking to connect with other families:

- LuMind IDSC hosts an annual Family Weekend at 19 Great Wolf Lodge resorts across North America. A unique and popular tradition, the next Family Weekend will take place September 16 to 18, 2022. For more information, visit: [www.LuMindIDSC.org/familyweekend](http://www.LuMindIDSC.org/familyweekend)
- Join the 260,000+ families in the LuMind IDSC community on social media:
  - ◆ **Facebook:** [www.facebook.com/LuMindIDSC](http://www.facebook.com/LuMindIDSC)
  - ◆ **Instagram:** [www.instagram.com/lumindidsc](http://www.instagram.com/lumindidsc)
- Our community hosts 15 audience-driven Facebook groups, designed to facilitate peer-to-peer support for a wide variety of people with ties to Down syndrome. Learn more online at [www.facebook.com/LuMindIDSC](http://www.facebook.com/LuMindIDSC)

As outlined above, MyDSC is a free, online platform filled with Down syndrome-specific information. Here are some highlights of useful resources that can be found in the myDSC resource library:

Anyone can access this library of information via myDSC online at [www.myDSC.org](http://www.myDSC.org). Registering requires three easy steps:



### ABOUT THE AUTHOR:

Hampus Hillerstrom is President/CEO of LuMind IDSC Foundation. Previously, he co-founded and served in executive roles at biotech company Proclara Biosciences. Hampus also worked at the venture capital firm HealthCap, pharma company AstraZeneca, and investment bank Lazard. Hampus holds a master's degree in economics from University of St. Gallen, MBA from Harvard Business School, and MSc in Health Sciences and Technology from MIT/Harvard. Hampus lives in the Boston area with his wife and children. Their oldest son, Oskar, has Down syndrome.