



# Our 2021 IMPACT: thanks to donors like you!

## 280,000

Social Media followers on five platforms.

## 500

community members participated in our webinars and podcasts.

## 500+

caregivers responded to a research survey about the unique challenges of caregiving.

## 2500

children, teens, parents, siblings, caregivers, and friends attended **Family Weekend** at 18 Great Wolf Lodge locations in the U.S.

## 265,000

### myDSmoment

People engaged in a first-of-its-kind **Research Awareness Campaign** which invites the community to learn more about Down syndrome research, the steps involved, and how their voices can be amplified.

### myDSC

our free, online community resource has grown to...

## 1640

members in

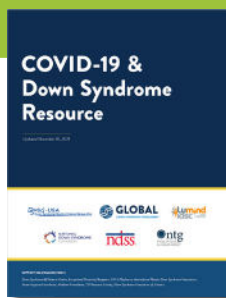
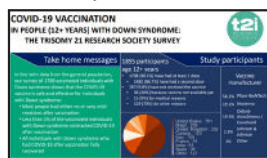
## 44

states

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

## In 2021, we also...

Continued to offer up-to-date information, communications, and vetted resources regarding **COVID-19** and **vaccines**.



## FUNDRAISE YOUR WAY my321

Launched **my321**, a personal fundraising platform for athletes, families, and advocates to raise funds and advance our mission.

# Consortium launch: 1<sup>st</sup> of its kind

## RESEARCH CONSORTIUM



LuMind IDSC officially launched a multi-million-dollar **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.

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).

## Policymaking at the federal level : CPIM meeting

18

FDA employees

8

academic and research institutions

10

life sciences companies

5

community members and caregivers

5

clinical and medical experts

FDA

U.S. FOOD & DRUG  
ADMINISTRATION

## In 2021, we also...

5

peer-reviewed research articles were published in clinical and scientific journals.

LuMind IDSC 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. LuMind IDSC issued several statements and blogposts, and hosted a webinar related to Aduhelm as a means of sharing accurate information. We do not know at this stage if this drug is safe or effective for people with DS. What remains clear is there is much to learn about the drug and **LuMind IDSC** is committed to staying actively involved.



Down Syndrome  
Clinical Trials Network

Expanded **LIFE-DSR**, a natural history study in the DS-CTN to include:

- four new biomarkers
- expanded blood collection sub-studies
- two feasibility studies on Alzheimer's assessment scales designed for people with Down syndrome. Enrollment is ongoing.

170

individuals have enrolled to date

14

sites

10

states

3

sites now enrolling the recently-launched Goal Attainment Scale sub study

