THE ADVOCATE TIMES

national down syndrome society ndss

THE NATIONAL DOWN SYNDROME SOCIETY: A Year of Impact and Advocacy

NDSS & LuMind IDSC: A Merger That Multiplied Our Impact

Nearly one year after LuMind IDSC Foundation merged into NDSS, we are reaching more people, advancing important research and health initiatives, and building a stronger national platform for the Down syndrome community than ever before. As a unified organization, we are positioned to drive progress by accelerating research, improving access to quality healthcare, shaping inclusive public policy, and shifting public perception.

By adding research as a new pillar, NDSS is better positioned to deliver on our new mission:

To create a world where individuals with Down syndrome thrive.

Building the Future of Down Syndrome Research

NDSS is leaning into our role as a leader in Down syndrome research, with an initial focus on Down syndrome-associated Alzheimer's disease (DS-AD), as well as investments in initiatives that improve the health and well-being of individuals with Down syndrome. Individuals with Down syndrome have a 90% lifetime risk of developing DS-AD. We're meeting this critical challenge by leading a coordinated national strategy to raise awareness, educate healthcare professionals, engage the research community, and equip families to make informed decisions about healthcare and clinical trial participation.

90% of adults with Down syndrome have a lifetime risk of developing DS-AD

In 2026, NDSS:

- Partnered with Conifer Research to survey 200 caregivers to identify key barriers in research participation and generate insights to inform our Alzheimer's work.
- Convened 160 participants for the Down syndrome community's first **Patient-focused Drug Development Meeting (PFDD)** with the FDA to share experiences with DS-AD to inform future treatment and regulations.
- Coordinated stakeholder engagement meetings for a new sleep apnea clinical trial from the University of Arizona.
- Completed the second cohort of **Pathways to Parity**, a curriculum to educate self-advocates & caregivers on DS-AD research.
- Developed **MinDSet Down Syndrome Training** to train researchers on creating a study environment that welcomes individuals with Down syndrome.

NDSS By the Numbers

RESOURCES & SUPPORT

In the last 12 months:

12
New guides and resources developed

10,000+
Registrations across more than 25 webinars

20,000+
Resource downloads

4,000+
Community inquiries via Helpline & info email

$45,800
Awarded in community scholarships

733,000
New website users (+9%)

Most downloaded resources:

1. Women's Health Guide
2. Alzheimer's Guidebook
3. Inclusive Education
4. A Promising Future Together: Guide for Expectant Parents
5. *321go!* Program Guide

BRIGHTER FUTURES Conference

A National Gathering on Adulthood and Aging

NDSS partnered with Massachusetts Down Syndrome Congress to welcome 350 attendees from 24 states to the **Brighter Futures Conference**. Self-advocates, families, and professionals participated in 75 workshops on the latest research on Alzheimer's disease, health, employment, and inclusion.

HEALTH & WELLNESS

CARE Down Syndrome Reaches Clinicians Nationwide

With only 5% of adults with Down syndrome having access to specialty medical care, CARE Down Syndrome launched in October 2025 to address unmet needs in the community. This, free, CME accredited online education hub is designed to help healthcare professionals deliver high-quality, respectful care to adults with Down syndrome.

This past year:

- 417 individuals registered for the foundational eLearning course, with 272+ completions
- 100% of evaluation respondents said they were likely to share it with a colleague; 92% agreed the content met its educational objectives
- Expanded into Canada through a partnership agreement with the Canadian Down Syndrome Society

ONLY 5% of adults with Down syndrome have access to specialty medical care

COMMUNITY HIGHLIGHT

The Gift of a College Experience

With support from an NDSS scholarship, Audrey spent her freshman year at ClemsonLIFE making friends, joining clubs, and discovering just how much she's capable of.

Through this program, Audrey is developing important real-world skills, including managing a bank account, navigating new technology, and preparing for job interviews. Outside the classroom, she threw herself into campus life, swimming with the Clemson club swim team, riding horses through the equestrian program, and learning to cook with volunteer mentors.

"Being a student at ClemsonLIFE has been life changing."
— Audrey

As she looks ahead to her sophomore year, Audrey is grateful for the chance to call herself a college student.

Your support made this year possible.
Thank you!

Learn more and get involved at www.ndss.org

321go! Brings Wellness to More Families Than Ever

321go! is a program designed to improve quality of life for individuals with Down syndrome by building healthy, lasting habits. Using a behavior-change model, *321go!* engages the whole family to make healthy choices easier, more sustainable, and fun.

This past year NDSS:

- Distributed 300 Fitness Kits
- Launched the eight-week *321go!* curriculum at six new local organizations
- Launched an online program portal for local organizations to easily access all materials

> ***We have offered the program four times now, it truly is 'plug-n-play' and makes it easy for our team to use."***
> — Down Syndrome Association of Central Ohio

ADVOCACY & PUBLIC POLICY

A Year of Policy Progress

This past year:

- The **ENABLE Act** was signed into law in July 2025, making permanent key improvements to ABLE accounts
- The **Down Syndrome Advocacy Conference** drew 230+ advocates from 26 states and D.C. for 125+ Capitol Hill meetings
- The House Judiciary Committee passed the **Words Matter Act** on March 26th, which removes and replaces the R-word in U.S. Code

Charlotte's Bill Moves Closer Than Ever to Becoming Law

After years of advocacy, the **Charlotte Woodward Organ Transplant Discrimination Prevention Act** is closer to becoming law than ever before. In June 2026, the U.S. Senate Health, Education, Labor and Pensions (HELP) Committee advanced the bill, clearing the way for a vote before the full Senate. Named for NDSS Programs Associate Charlotte Woodward, the legislation would clearly prohibit discrimination on the basis of disability in the organ transplant system. With companion legislation already passed by the House of Representatives, the bill could be signed into law later this year.

"People with disabilities have inherent value and worth and should not be ignored in the organ transplantation process."
— Charlotte Woodward.