

THE ADVOCATE TIMES



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

Record-breaking year for NDSS

The National Down Syndrome Society (NDSS) is committed to engaging with our local communities and continuing to empower our families to thrive. In the last year, we:



Connected with **10,000+** families/individuals in person and virtually



Responded to **5,000+** requests for support through The NDSS Helpline



Awarded **\$60,000+** in scholarships to individuals with Down syndrome



Launched **Women's Health Guide**



Launched **Transitioning from School to Adulthood Guide**



22,400+ Digital resource downloads



664,000+ Website visits in the last 12 months

Charlotte's Bill passes the House

The **Charlotte Woodward Organ Transplant Discrimination Prevention Act** passed the full House of Representatives with broad bipartisan support. NDSS will continue to

champion the legislation and lead advocacy efforts in support of the bill, which will prevent individuals with Down syndrome and other disabilities from being denied life-saving care, simply because of their disability. Charlotte and her story were featured in *People Magazine*, generating important momentum for this issue. Stay tuned on ways you can take action to support Charlotte's Bill.



Charlotte Woodward, NDSS Staff and Advocate



Kayla McKeon, NDSS Staff and Advocate

Kayla McKeon named to Forbes' Accessibility 100

NDSS Manager of Public Policy, and first registered lobbyist with Down syndrome, Kayla McKeon, was recognized as part of the *Forbes'* Accessibility 100. Her fierce advocacy has helped advance critical legislation for people with

Down syndrome and other disabilities while shifting perceptions of what our community can achieve. "I'm a relentless advocate," she says. "I'll keep going and going, and make sure those nays turn into yeas."

Mattel expands line of Barbies with Down syndrome

NDSS, along with families in the community, once again partnered with Mattel to launch the Black Barbie® doll with Down syndrome. NDSS also supported the

creation and integration of this doll into the most recent Barbie YouTube series.



Our work is made possible by your support: www.ndss.org



NDSS helped us find our voice



Audrey Presby & Jeremy Fraser, hosts of *The Audrey & Jeremy Show*

by Audrey Presby & Jeremy Fraser

This year has been a big one for us, and NDSS has played a huge part in that journey. They've helped us use our voices to speak up—not just for ourselves, but for the entire disability community. From starring in Town 21 to participating in the Adult Summit and launching *The Audrey and Jeremy Show* podcast, we've had so many chances to share our message and lead with purpose. One of the biggest moments was attending the

NDSS Down Syndrome Advocacy Conference in Washington, D.C. We had the opportunity to meet with lawmakers and discuss issues that truly matter, such as inclusion, access, and equity. It was powerful and eye-opening. That trip gave us the confidence and tools to keep advocating, not just for us, but for others who still need to be heard. **NDSS has helped us grow, find our voice, and keep working to make a difference.**

Year in review

Adulthood and Aging

- **The National Alzheimer's Project Act (NAPA) Reauthorization Act** was signed into law in October 2024, ensuring individuals with Down syndrome are included in federal efforts to address Alzheimer's disease

- As a result of NDSS coordination, an individual representing the Down syndrome community provided public comment at every NAPA Council meeting
- 300+ individuals, caregivers, and professionals attended the NDSS Adult Summit in Costa Mesa, CA

40,000+
Advocacy emails, calls, and meetings with representatives

5,716
New advocates joined our work

400+
Attendees at the NDSS Down Syndrome Advocacy Conference

4
NDSS priorities signed into law

Employment

- In partnership with OUTFRONT media, NDSS launched a national billboard campaign promoting inclusive hiring and entrepreneurship shown on 580 billboards across 26 states

- NDSS launched our Holiday Gift Guide featuring 24 self-advocate owned businesses reaching more than 25,000 people
- Eleven op-eds published in support of National Disability Employment Awareness Month

Health Equity

- NDSS launched a new Health & Wellness newsletter
- Added three new resources – a Caregiver Toolkit, Sleep Apnea Overview, and Preparing for a Sleep Study
- Trained more than 200 genetic counselors

on delivering a proper Down syndrome diagnosis

- Supported clinical research participation for 28 studies, and wrote letters of support for 15 studies
- Made significant progress on a paradigm-shifting new initiative: **CARE Down Syndrome**



Coming soon

This October, NDSS will proudly launch one of its most ambitious initiatives to date: **CARE Down Syndrome**. This groundbreaking program delivers essential education and tools to improve healthcare quality and outcomes for adults with Down syndrome. A fully accredited course, **CARE Down Syndrome** will remove barriers to care by increasing the number of physicians with expertise in Down syndrome across the country.

Your support helped NDSS make a profound impact over the past year. *Thank you!*