



**North Carolina
Down Syndrome Alliance**
empower • connect • support

EMPOWER. CONNECT. SUPPORT.
TOGETHER WE CAN.



2024
ANNUAL REPORT

ABOUT NCDSA

MISSION

To empower, connect, and support the lifespan of individuals with Down syndrome, their families, and the community through outreach, advocacy, and education in North Carolina.

VISION

North Carolina Down Syndrome Alliance is an effective, compassionate, and comprehensive resource on Down syndrome throughout North Carolina. NCDSA envisions a culture in which all people with Down syndrome are empowered to achieve their full potential and live healthy, productive lives as valued citizens within the fabric of society.

MEET THE 2024 TEAM

AMY NAVEJAS	Executive Director
CHRISTY COOPER	Assistant Director
TORI ENGLAND	Program Coordinator
LIZA NARDUCCI	Operations Coordinator
BETSYJOHN LANE	Family Support Specialist
EMMA WISSINK	Family Support Assistant
STEFANI MERGEN	Family Navigator
COURTNEY DOZIER	Bookkeeper
ALYSSA JACOBS	Marketing & Social Media Coordinator



2024 BOARD OF DIRECTORS

JEFF LINEBERRY	President	ADAM CATO	Treasurer
TONY NICHOLSON	Vice President	SANTO CAIVANO	Secretary
DIANE CAVANAGH		NOEL MARSHALL	
MATT COOPER		TARA MOORE	
BETH COSGROVE		AMBER SCUTT-BROWN	
JESSE FOWLER		KATE WESTMORELAND, MD	
HEATHER HARRELL		VICKI WRIGLEY	
JASON HO, MD			



A LETTER FROM THE EXECUTIVE DIRECTOR

As we reflect on the past year, I am deeply grateful for the chance to pour into work that supports such amazing youth and adults. One of the challenges of working in such a passionate community is that every person you ask will have a different priority. With that in mind, in 2024, we worked to hone in on maximizing attainable and meaningful impact, best practice, and quality. Here's a look at a few of our achievements.

- Buddy Walk and Gala set new records for both attendance and fundraising
- Created a Board more reflective of the communities we serve
- Tripled our programmatic staff hours
- Hired a new Assistant Director to lead our restructured advocacy and outreach efforts
- Brought on a Family Navigator to offer families resources
- Full accreditation from Down Syndrome Affiliates in Action (DSAIA)
- First CPA review in over a decade, affirming our commitment to operational excellence and stewardship of donor funds
- Partnered with UNC Health to help support the launch of an interdisciplinary Down syndrome clinic
- Hosted our first T21 volunteer event, emphasizing that people with Down syndrome are capable of giving back and sharing their skills
- Grew existing programming participation numbers and established consistent Sandhills programming
- Emphasized stewardship of donor dollars and diversification of funding sources. NCDSA applied for and received over a dozen grants last year, growing both foundation and individual donor giving

That said, until 2024, NCDSA had received state overflow funding from Covid. The loss of that excess state funding had a significant impact on our budget. The growth of our fundraisers and grant dollars that we saw this past year was critical to the success of our organization.

Moving ahead, we are excited about the progress we've made and the work still to come. We are honored to be North Carolina's only grassroots, statewide Down syndrome organization. This year, I look forward to welcoming more new babies, laughing alongside more families, and executing our mission with our passionate Board and Staff.

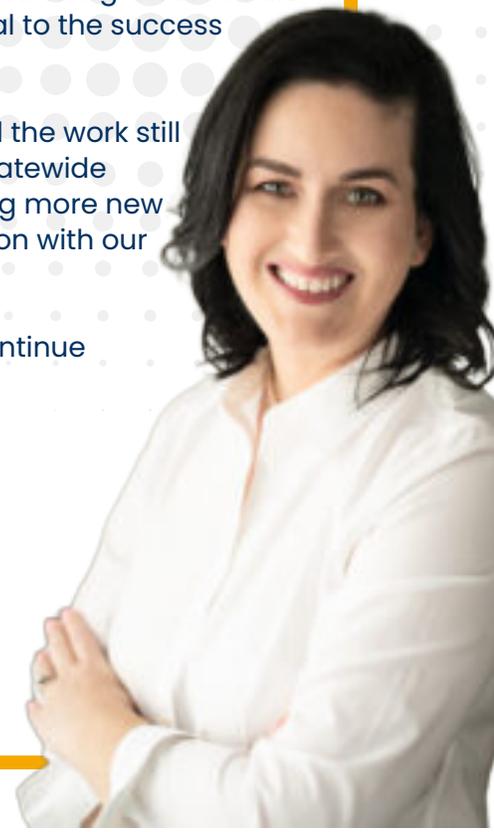
Thank you for being a vital part of our success. Together, we will continue to make a lasting difference.

With gratitude,

Amy Navejas, JD
Executive Director



**DSAIA
DOWN SYNDROME AFFILIATE
OF THE YEAR**



PROGRAM HIGHLIGHTS

MEDICAL OUTREACH

NCDSA is committed to serving people with Down syndrome, their families, and healthcare professionals. We assist clinicians in improving healthcare outcomes and quality of life for people with Down syndrome and their families by providing accurate, balanced, and up-to-date information.

NC FIRST CALL PROGRAM (FOR NEW & EXPECTANT PARENTS)

We believe every baby deserves a joyful welcome. We have a variety of accurate, up-to-date resources for new and expectant parents, and can connect you with a parent mentor who has walked in your shoes.



LEARNING PROGRAM

The Learning Program complements formal instruction in literacy and math, with occupational and speech therapy components, using research-based teaching strategies and customized materials to support families of children with Down syndrome in the educational process.

NORTH CAROLINA DOWN SYNDROME CONFERENCE

Held annually in the spring, the statewide conference brings together nationally and regionally recognized experts in their fields. Conference sessions cover diverse topics relevant across the lifespan of individuals with Down syndrome. Everyone who supports a person with Down syndrome and other intellectual disabilities is encouraged to attend.



T21 CLUB

Calling all teens and adults! NCDSA hosts events every month like bingo, glow parties, socials, and improv just for teens and adults with Down syndrome.

SIBSHOPS

Sibshops provide siblings of kids with Down syndrome with peer support and information in a lively, recreational setting. Events are hosted monthly in a variety of fun locations.

ANNUAL GALA

Join us as we unite to celebrate community and strive toward an inclusive future for individuals with Down syndrome.

T21 MOM'S RETREAT

Moms, this one's just for you! Take a weekend to yourself to recharge while you connect with fellow moms of children with Down syndrome. We'll take care of the meals and itinerary, you put your feet up and relax without the kids.

COMMUNITY IMPACT



RAISED

\$310,000+

2024
TRIANGLE BUDDYWALK
national down syndrome society®
EDUCATE | ADVOCATE | CELEBRATE



12,096 MEALS PACKED

for Western NC families by **69** volunteers during our first ever group T21 Gives Back event



WELCOME BABY/ NEW FAMILY BAGS DISTRIBUTED



12 GRANTS APPROVED

4 REGIONS OF NC TOUCHED BY IN-PERSON EVENTS

Western, Triangle, Eastern, Sandhills



66 T-21 CLUB
12 in-person events
54 virtual events



NEW FOR 2025

LOOKING FORWARD



UNC DOWN SYNDROME CLINIC



Every person with Down syndrome deserves access to healthcare that improves their quality of life. One of our key objectives as an organization is to make this a reality for NC families.” – Amy Navejas, Executive Director, NCDSA



We have established a groundbreaking partnership between North Carolina Down Syndrome Alliance (NCDSA) and the University of North Carolina (UNC) Health to create the UNC Down Syndrome Clinic! Coming in 2025, this comprehensive program will unite top-tier expertise and offer specialized medical care for individuals with Down syndrome, from infancy through adulthood, to enhance their health and well-being.



DR. KATE WESTMORELAND, UNC PEDIATRICIAN, NCDSA BOARD MEMBER AND MOTHER OF A 2-YEAR-OLD WITH DOWN SYNDROME



WORLD DOWN SYNDROME DAY CLASSROOM KITS



As part of our outreach efforts to increase awareness and inclusion, we have created free World Down Syndrome Day classroom kits for NC classrooms! The supplies are graciously sponsored by the Carolina Hurricanes and another private foundation grant. Kits include a lesson plan, PowerPoint presentation, video link, two classroom crafts, book about Down syndrome, note to send home to parents about the lesson, themed baseball cards for each student, and an "Ask Emma" section to submit any lingering questions.

NCDSA SUMMER CAMP

The NCDSA summer camp will return in the summer of 2025, offering two week long sessions open to children with Down syndrome and their siblings!



A YEAR IN REVIEW

20
24





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LET'S CONNECT

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