

















2022 ANNUAL REPORT

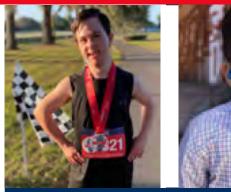
The leading human rights organization for all individuals with Down syndrome.





MISSION STATEMENT

The National Down Syndrome Society is the leading human rights organization for all individuals with Down syndrome.



VISION STATEMENT

The National Down Syndrome Society envisions a world in which all people with Down syndrome have the opportunity to enhance their quality of life, realize their life aspirations, and become valued members of welcoming communities.

NDSS PROGRAMS

Founded in 1979, NDSS supports and advocates for the Down syndrome community by focusing on three key areas of programming: Resources & Support, Policy & Advocacy, and Community Engagement. Within these focus areas NDSS engages in various activities, events, and programs on topics that are critical to our community, such as federal and state advocacy and public policy, health and wellness, education, and employment. NDSS creates resources to support individuals with Down syndrome, their families, and caregivers across the lifespan and hosts awareness and engagement events throughout the country including the National Buddy Walk® Program, the Times Square Video presentation and New York City Buddy Walk®, Racing for 3.21 on World Down Syndrome Day, Run for 3.21, DC Golf Outing, the annual NDSS Gala & Auction, and others.

NDSS BOARD OF DIRECTORS

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LETTER FROM LEADERSHIP

Dear Friends,

Last fiscal year was a pivotal one for the National Down Syndrome Society (NDSS), and we are so grateful to our supporters for making it a year of tremendous impact for the Down syndrome community. We moved from virtual to in-person events, reconnected with supporters and built new friendships at conferences across the country, strengthened relationships with organizations in the Down syndrome space and beyond, and tirelessly pursued our mission.

Our 2021-2022 Annual Report provides an overview of our core programs and highlights some of the critical ways we advocated for and supported individuals with Down syndrome and their families this past year. Our education, employment, and health and wellness teams provided our community resources and information through conferences, videos, publications, and one-on-one support. As the leading human rights organization for all individuals with Down syndrome, we worked with our grassroots advocates and partners to pursue critical legislation and regulatory policy concerning organ transplant discrimination, wage equity, access to education, and the emerging need for greater inclusion concerning Alzheimer's disease and Down syndrome. Our community engagement staff continued to share information, raise awareness, build connections, and celebrate individuals with Down syndrome through social media, events, and our new website.

NDSS makes an impact because of our volunteers, our partners, and our corporate, foundation, and individual donors. As we look ahead, we are tremendously thankful for those who have supported us over the past 43 years and to all who will join our NDSS family in the year ahead.

With gratitude,

Kandi Pickard President & CEO

Tiffany Barfield Chairwoman



RESOURCES & SUPPORT

As a critical part of our work to advocate for and support the Down syndrome community, NDSS provides free information on topics across the lifespan from birth to end of life through our website, webinars, resources, events, and publications. These efforts include a focus on the critical areas of education, employment, and health and wellness.

Through our helpline and info email, NDSS also answers thousands of requests for information each year, responding to questions and connecting families with our network of more than 250 local Down syndrome organizations across the country.

Education

The NDSS Education Program is developing a continuum of systems-level supports for students with Down syndrome and their families. We believe access to an education is a civil right, and the opportunity to learn is the key to a fulfilling life and the foundation of an equitable society. In pursuit of our mission to advance inclusive education across the country, the NDSS education team provides resources, programming, and supports for families, educators, and advocates. We work to influence policy at the federal, state, and local levels to ensure that people with Down syndrome can access the education to which they are entitled and that the quality of that education is continually improved.

In FY22, NDSS finalized and distributed a new and extensive resource to support the education of individuals with Down syndrome. Created in collaboration with Down Syndrome Education International, Down Syndrome: Guidelines for Inclusive Education is the first document of its kind in the United States. The document addresses the education settings that support students with Down syndrome, covering the period from early intervention and primary education through secondary and higher education, with the primary focus being K-12 students. In the first six months, the resource was downloaded more than 2,500 times.



Employment

The NDSS Employment Program is increasing access to the workforce for people with Down syndrome. Through collaboration with NDSS affiliate organizations, employers, government agencies, and other key stakeholders, NDSS creates meaningful change in the professional lives of people with Down syndrome across the country. Specifically, NDSS advocates for policies that increase access to competitive integrated employment for individuals; provides valuable resources, support, and training to the community; offers technical assistance to corporations; and highlights the success of employees and business owners with Down syndrome.

During the 2022 fiscal year, NDSS established new connections with companies, government leaders, and service organizations to improve school-to-work transition services, advance public policy priorities such as wage equity for people with disabilities, and provide guidance to companies working to increase workplace inclusion. We also continued our efforts to highlight the many kinds of work individuals with Down syndrome are doing through online storytelling, a video interview series called Business Spotlights by Charlotte, and by supporting and promoting businesses owned and run by individuals with Down syndrome.



Leading the way to an inclusive workforce.

NDSS is a proud founding member of the CEO Commission for Disability Employment. Co-founded with the Society for Human Resource Management (SHRM) and Voya Financial, the CEO Commission serves as a resource for the executive community to access research, information, and advocacy opportunities to build and promote disability inclusive practices in their organizations. In support of the Commission last year, NDSS hosted webinars on topics such as universal design and disability inclusive branding, published several educational resources, and participated on panels at the SHRM Inclusion Conference and the Harkin International Disability Employment Summit.

Health & Wellness

The NDSS Health and Wellness Program promotes improved health and wellbeing for all individuals with Down syndrome. Through collaboration with NDSS affiliate organizations, Down syndrome clinics, researchers, government agencies, and other key stakeholders, NDSS develops tailored and accessible resources for individuals with Down syndrome, families, and caregivers. Addressing topics across the lifespan from prenatal diagnosis to aging adults, NDSS offers guides, one-pagers, online resources, and conferences to provide information and support to the Down syndrome community.

NDSS Adult Summit

A key pillar of our Health & Wellness Program is the NDSS Adult Summit. As the life expectancy for individuals with Down syndrome increases, NDSS is committed to ensuring our adults with Down syndrome, their families, caregivers, and other key stakeholders have the best, most accurate information on adulthood and aging. Supported by our generous sponsors, the 2022 Adult Summit: On the Road provided opportunities to learn about topics relevant to various age groups in three cities across the country, or online. Two of the three conferences took place during the 2022 fiscal year.



In March, we gathered in Jacksonville, Florida for learning sessions focused on supporting aging adults. The event included presentations from the Alzheimer's Association, the Healthy Brain Initiative, Mayo Clinic in Florida, LuMind IDSC, Global Down Syndrome Foundation, and the National Institutes of Health. A full day at this conference was dedicated to sharing and discussing research, studies with physicians and researchers. Families learned about the latest research and physicians and researchers were able to interact and learn from each other and members of the community.

In June, we traveled to Indianapolis, Indiana for sessions focused on preparing for the transition from pediatrics into adult life. Caregivers, parents, professionals, and individuals with Down syndrome learned about education, employment, community integration, and independence, as well as safety and law enforcement, staying healthy with NDSS' new 321go! program, and engaging in the arts.



Alzheimer's disease and Down syndrome

NDSS has taken a lead role on this emerging and critical health issue, especially over the past year. Through resources and advocacy, we are working to support families and caregivers and to ensure individuals with Down syndrome have equitable access to diagnosis, treatment, and care. Our multilayer approach utilizes policy, media, and community outreach to advocate for greater awareness and support for our community. This past year, NDSS was consulted by the Washington Post, Forbes, and NPR for media pieces on the connection between Down syndrome and Alzheimer's disease and the need for greater inclusion. We also participated in critical advocacy efforts in collaboration with partner organizations and grassroots advocates (see page 7).

321go!

In 2022 NDSS developed the *321go!* program to promote healthy lifestyle choices in physical activity, balanced nutrition, and emotional wellness among individuals with Down syndrome and their families. The foundation of the *321go!* program is a set of 3 goals and 21 challenges that encourage a daily focus on overall wellbeing. Resources for the program provide education, support goal setting, and foster independent skills. We look forward to continuing to develop additional resources in the coming years as we expand our focus on healthy living.



POLICY & ADVOCACY

The NDSS Advocacy & Public Policy Program champions federal, state, and local policies that positively impact all people with Down syndrome across the country. Through our grassroots advocacy program, NDSS works with Congress and federal agencies, as well as state and local officials, to develop and improve laws, regulations, and policies for the benefit of the Down syndrome community. NDSS also empowers self-advocates, parents, and others to influence policy themselves. The NDSS legislative agenda spans the life experience of individuals with Down syndrome from birth to adulthood, centered on five important areas: healthcare and research, education, economic self-sufficiency, community integration, and employment.





Thanks to the hard work of our grassroots advocates and staff, during the 2022 Fiscal Year:

- More than 2,000 grassroots advocates were informed of critical legislation and took action to contact their representatives.
- New federal legislation, the ABLE Employment Flexibility Act, which would enable employers to help their employees with disabilities pay for qualified disability expenses, was introduced.
- Federal legislation named for Charlotte Woodward, a member of NDSS' staff, was reintroduced in the House and introduced for the first time in the Senate.
- State bills prohibiting discrimination in organ transplantation against people with disabilities passed in Arizona, Mississippi, Nevada, North Carolina, South Dakota, West Virginia, and Wisconsin.
- · Legislation to phase out subminimum wage was passed in Rhode Island, South Carolina, and Tennessee.
- Hundreds of law enforcement officers and first responders in Indiana, Kentucky, Pennsylvania, and West Virginia received training on how to promote safe interactions with individuals with disabilities in their communities.

Down syndrome and Alzheimer's disease

NDSS has been working to spread awareness of the link between Down syndrome and Alzheimer's disease and advocating for meaningful governmental action to support our community. Throughout the year, NDSS participated in quarterly meetings of the Advisory Council on Alzheimer's Research, Care, and Services, a federal group that meets to discuss programs that impact individuals with Alzheimer's disease and their caregivers. It is critical that this body focused on Alzheimer's disease include the Down syndrome community in its efforts.

Additionally, NDSS provided feedback to the Centers for Medicare & Medicaid Services (CMS) on several matters related to Alzheimer's disease. One of these was a response to a proposed coverage determination that would have excluded the Down syndrome community from the process related to a new, experimental treatment for Alzheimer's disease. Because it was the first of its kind, exclusion would have set the Down syndrome community behind other patient populations and denied the medical community the data it would need to help health care providers and families make informed decisions about whether this drug was right for patients with Down syndrome. In response, NDSS facilitated a public-facing, multi-organizational effort with other national Down syndrome organizations, an incredibly successful strategy that brought about one of the single largest outpourings of public comment in CMS history, significantly elevating agency awareness of our community's interest and influence – and resulting in CMS' rescission of the proposed exclusionary policy.





Down Syndrome Policy Symposium

In April 2022, NDSS hosted the first Down Syndrome Policy Symposium in Washington, D.C. The meeting served as an opportunity for the six largest Down syndrome organizations in the U.S. to build better working relationships and concrete strategies aimed at tackling policy issues critical to the Down syndrome community. Participants included Down Syndrome Affiliates in Action (DSAIA), GiGi's Playhouse Down Syndrome Achievement Centers, Global Down Syndrome Foundation (GLOBAL), LuMind IDSC Foundation (LuMind IDSC), the National Down Syndrome Congress (NDSC), and the National Down Syndrome Society (NDSS). Disability rights pioneer Judy Heumann joined NDSS' own Kayla McKeon for a Q&A to close out the event.



COMMUNITY ENGAGEMENT

Our community engagement events and activities celebrate our loved ones with Down syndrome, raise awareness and acceptance among the general public, fuel our mission, and connect individuals and families within the community. During the past year, more than 5,000 supporters helped raise awareness and acceptance of individuals with Down syndrome through participation in one or more of our nationwide events. Through our scholarships, grants, and awards program, we provided \$45,200 in grants to 41 individuals with Down syndrome.

NDSS Scholarships, Grants, and Awards

NDSS is proud to offer various scholarships, grants, and awards that recognize the tremendous contributions of individuals with Down syndrome and provide opportunities for them to enhance their lives through education, business, or other passions. We are grateful to the organizations and families who make these possible.

2022 Dan Piper Award: In Memory of Mia Peterson

Mia Peterson made significant contributions to improving the lives of individuals with disabilities as the first NDSS board member with Down syndrome, a public speaker, and an active advocate for legislative change. Mia's life is a powerful example of the tremendous impact individuals with Down syndrome have in their communities. NDSS was grateful to be able to honor Mia's memory with the Dan Piper Award during the virtual New York City Buddy Walk on September 18, 2021.



Voya Cares Entrepreneurship Grant

In partnership with Voya Cares, NDSS provided a \$10,000 grant to Adam DeBacker to invest in his business, Truffles E Truffles. Adam, a recent graduate with a Bachelor of Science in Theatre from Missouri State, has been making truffles for 15 years. With the support of the grant, Adam has been able to expand Truffles E Truffles to do more retail and wholesale business. Adam has seen a 300% increase in sales since the announcement that he received this grant.



Adams & Giannou Community Involvement Scholarship

The mission of the Adams & Giannou Community Involvement Scholarship is to recognize individuals with Down Syndrome for enriching the lives of others. Six deserving self-advocates who demonstrated a passion for supporting their local community through service or volunteering and who exemplified Marianna Adams' passion for helping others were selected to receive a scholarship.

Nina Koster

Justin Gursinski

Miles Evans

Faith-Christina Duncan

Kechia Kinsey

Kirk Daum



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Blake Pyron Entrepreneurship Scholarship

The Blake Pyron Entrepreneurship Scholarship was established with the goal of supporting selfadvocates as they pursue their dreams of owning their own business. The recipients receive \$500 to invest in their business.

Nate Seagraves

Andrew Patterson

Brandon Gruber Scholarship

The Brandon Gruber Scholarship was established with the goal of supporting self-advocates as they pursue their passion for visual and performing arts. Each year, Brandon selects three individuals over the age of 18 to receive this scholarship to help launch or continue their passion for visual or performing arts instruction.

Kayla Snover

Marisa Tellalian

Easton Reyes

Hallie McCollum

Ian Dischinger

Abby Reuter

Ethan Saylor Memorial Scholarship

Ethan Saylor lived his life to the fullest. Whether it was rocking out to music, working with law enforcement, or playing the guitar, when Ethan wanted to do something, nothing was going to stop him. Each year, NDSS awards a \$500 scholarship to an individual who embodies the same energy Ethan carried with him. Two individuals received awards between July 1, 2021 and June 30, 2022.

Bradley Carlise

Faith-Christina Duncan

O'Neill Tabani Enrichment Fund

The O'Neill Tabani Enrichment Fund provides grants that will benefit individuals with Down syndrome of all abilities as they pursue postsecondary education or enrichment classes. Since its founding in 2005, more than \$275,000 has been awarded, allowing 200 young adults with Down syndrome to take college courses, receive vocational training, or pursue a love of music, art, or other experiences through enrichment classes.

Amanda Altemus

Kylie Andrews

Megan Caldwell

Faith-Christina Duncan

Taylor Freeman

Alexandra Griffin

Rachel Handlin

Martha Haythorn

Samuel Jordan

Hari Kannan

Ning Koster

Hallie McCollum

Nick Menard-Freeman

Ryan Mosley

Sarah Parrack

Jackson Ray

Anna Reagle

Maggie Scherder

Sophia Spizzirri

Jacob Stives

Summer Stout

Kiernan Treptow

Joshua Williams

COMMUNITY ENGAGEMENT (CONTINUED)

NDSS Events

National Buddy Walk® Program

Since 1995, the National Buddy Walk Program has promoted acceptance and inclusion of people with Down syndrome and raised funds for local and national organizations that support people with Down syndrome and their families. Annually, hundreds of thousands of participants take part in local Buddy Walks across the country. The COVID-19 pandemic continued to have an impact on many local events last year. Still, 135 local groups held inperson or virtual walks and were supported by NDSS with resources, monthly webinars, and reduced licensing fees.



Times Square Video Presentation and New York City Buddy Walk®

The annual Times Square Video kicks off our NYC Buddy Walk® each year, projecting photos of 500+ individuals with Down syndrome on the giant screens of Times Square. On September 18, 2021, thousands of individuals joined us from their homes across the country to view the video presentation before the virtual 2021 New York City Buddy Walk. The live-streamed kick-off video featured emcee Chris Wragge from CBS2 in NYC, grand marshals Sophie Slack and Kristian Thomas, a video honoring the memory of Dan Piper Award recipient Mia Peterson, and more. Throughout the day participants posted photos on social media as they raised awareness and walked in communities across the country.







THE BEST IS YET TO COME





36th Annual Gala & Auction and A Night of Celebration

In March, NDSS hosted two special events. Both evenings were filled with celebration, inspiration, and purpose as attendees supported NDSS programs that enhance inclusion, uphold human rights, expand opportunities, and provide support for the Down syndrome community.

On March 10, NDSS held our 36th Annual Gala & Auction at the beautiful Cipriani 25 Broadway in NYC. Guests enjoyed unique cocktails, delicious food, an exciting live auction, entertainment by violinist Emmanuel Bishop, and more.

A week later, hundreds of viewers gathered online for A Night of Celebration honoring David Egan, a renowned trailblazer and advocate with Down syndrome. Savannah Guthrie from NBC News' TODAY and NDSS Public Outreach Associate David DeSanctis emceed the event, which included entertainment by award-winning illusionist Matias Letelier and a fabulous online auction.











Run for 3.21

Our annual Run for 3.21 event celebrated its fifth year with teams of runners in two locations. In addition to our traditional East Coast

run in March, we took on a new challenge on the West Coast in September. Supported by our generous in-kind sponsors, the teams collectively raised more than \$170,000 for NDSS programs.



country took on the 340-mile journey from the Santa Monica Pier in CA to Las Vegas, NV. This new route provided a rigorous challenge to the team, requiring each member to complete roughly 340 miles through mountains and deserts.

From September 3-5, 2021, a team of 10 elite runners from across the



Then, March 19-21, 2022, a team of 25 runners representing 12 states completed our annual 260-mile relay-style adventure from the United Nations in NYC to the steps of the U.S Capitol in Washington, D.C.



Racing for 3.21 on World **Down Syndrome Day**

On March 21, 2022, our sixth annual Racing for 3.21 on World Down Syndrome Day virtual event attracted thousands of participants from across the country. This annual event encourages participants to run, walk, bike, hike, swim, etc. for 3.21, 32.1, or 321 miles at any time, any place,

and at any pace to celebrate and raise awareness for the Down syndrome community during the month of March and on World Down Syndrome Day, March 21.



Since launching the NDSS Athlete Ambassador Program in 2017, the team has attracted more than 325 dedicated athletes from the Down syndrome community. The 2021-2022 Athlete Ambassador team included 115 individuals actively involved in sports such as running, swimming, cycling, triathlons, and more. The program offers various opportunities to build community and highlight the success of athletes representing NDSS globally.





Charity Racing

This past year saw the return of in-person racing, and runners from across the country were excited to participate in our charity racing program. More than 125 runners raised awareness and funds through runDisney events and the New York City Marathon. Collectively, they raised over \$123,000 to support advocacy and resources through NDSS.



Join NDSS for an event or conference in 2023!

Gala & Auction (New York City) – March 2

Run for 3.21 (NYC to DC) – March 17-19

Racing for 3.21 on World Down Syndrome Day (virtual) – March 21

Down Syndrome Advocacy Conference (Washington, DC) - April 17-19

Times Square Video and New York City Buddy Walk (New York City) – Sept TBD

NDSS Golf Outing (Alexandria, VA) - Sept/Oct TBD

Adult Summit (Cincinnati, OH) – Oct/Nov TBD

Tremonti Sings Sinatra

Grammy award-winning vocalist and quitarist Mark Tremonti released an album with all proceeds benefiting NDSS. Tremonti Sings Sinatra is a collection of 14 covers of classic Frank Sinatra tunes, recorded with surviving members of Sinatra's band and other top-notch musicians. A pre-launch concert and auction was held in Orlando, FL in mid-May raising nearly \$100,000. Additional concerts are scheduled for London in December 2022 and at the NDSS Gala in New York City in March 2023.





Ensure a brighter future for individuals with Down syndrome through a legacy gift.

NDSS envisions a world in which all people with Down syndrome have the opportunity to enhance their quality of life, realize their life aspirations, and become valued members of welcoming communities. Your legacy can make that vision a reality.

Legacy giving or planned giving is a meaningful way you can impact the future of individuals with Down syndrome while you and your family receive the benefits of smart financial planning. A legacy gift could be your most powerful and lasting contribution, improving the way babies with Down syndrome are welcomed; changing the way schools, businesses, and communities include our loved ones; and ensuring our adults have the care they need to live healthy, rewarding lives as they age.

Please contact Sara Goldberg, vice president of strategic development at sgoldberg@ndss.org or 301-801-0552 0552 for a confidential conversation about legacy giving.

To assist you with gift and estate planning, the official name, ddress, and tax ID for NDSS is:

National Down Syndrome Society 1155 15th Street NW, Suite 540, Washington, DC 20005 EIN/Tax ID: 13-2992567



FINANCIALS

Assets Unaudited Audited Cash and cash equivalents \$372,315 \$1,331,021	
Cash and cash equivalents \$372,315 \$1,331,021	
Contributions receivable \$41,296 \$46,490	
Investments, at fair value \$12,485,685 \$13,795,485	
Prepaid expenses and other assets \$158,650 \$75,052	
Property and equipment, net \$18,764 \$16,117	
TOTAL ASSETS \$13,076,710 \$15,264,165	
Liabilities and Net Assets LIABILITIES	
Accounts payable and accrued expenses \$426,769 \$179,446	
Note payable - PPP - \$212,805	
Deferred rent \$75,089 \$86,264	
Deferred revenue \$37,419 \$67,169	
TOTAL LIABILITIES \$539,277 \$545,684	
NET ASSETS	
Without donor restrictons:	
Undesignated \$3,192,168 \$3,726,276	
Designated by the Board for endowment \$7,842,897 \$9,192,680	
\$11,035,065 \$12,918,956	
With donor restrictons:	
Time and purpose restrictions \$428,927 \$726,084	
Endowment fund \$1,073,441 \$1,073,441	
\$1,502,368 \$1,799,525	
TOTAL NET ASSETS \$12,537,433 \$14,718,481	
TOTAL LIABILITIES AND NET ASSETS \$13,076,710 \$15,264,165	

Statements of Activities for FYE 6-30-2022 (With Summarized Comparative Information for FYE 6/30/21)

		FYE 6/30/2022				FYE 30-Jun-21
	_	Without Donor Restrictions	Program and Time Restric- tions	Endowment Funds	Total	Total
		Unaudited	Unaudited	Unaudited	Unaudited	Audited
Revenue and Other Support						
Contributions		\$2,222,829	\$214,442	-	\$2,437,271	\$2,119,722
National Buddy Walk		\$169,793	-	-	\$169,793	\$15,267
In-kind contributions		\$245,206	-	-	\$245,206	\$210,118
Special events	\$651,412.00	-	-	-		-
Less: direct benefit costs	(262,379.00)	\$389,033	-	-	\$389,033	\$415,931
PPP		\$212,805	-	-	\$212,805	\$219,087
Miscellaneous income		\$18,629	-	-	\$18,629	\$15,470
Net assets released from restrictions		\$275,991	(275,991)	-	-	-
Total revenue and other support		\$3,534,286	(61,549)	-	\$3,472,737	\$2,005,595
Expenses						
Program services						
Public and advocacy		\$678,784	-	-	\$678,784	\$683,442
Resourses and support		\$784,583	-	-	\$784,583	\$521,986
Community engagement		\$1,172,413	-	-	\$1,172,413	\$959,854
Total program services		\$2,635,780	-	-	\$2,635,780	\$2,165,282
Support services						
Management and general		\$455,278	-	-	\$455,278	\$285,622
Fundraising		\$428,745	-	-	\$428,745	\$309,460
Total supporting services		\$884,023	-	-	\$884,023	\$595,082
Total expenses		\$3,519803		-	\$3,519,803	\$2,760,364
Change in net assets before investment income (loss)		\$14,483	(61,549)	-	(47,066)	\$235,231
Investment (loss) income		(1,898,374)	(235,608)	-	(2,133,982)	\$2,739,690
Change in net assets		(1,883,891)	(297,157)	-	(2,181,048)	\$2,974,921
Net assets, beginning of year		\$12,918,956	\$726,084	\$1,073,441	\$14,718,481	\$11,743,560
Net assets, end of year		\$11,035,065	\$428,927	\$1,073,441	\$12,537,433	\$14,718,481



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CONTACT INFORMATION

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SOCIAL MEDIA

Facebook: @NDSS1979

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O Instagram: @ndssorg

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TikTok: @ndssorg

in LinkedIn: national-down-syndrome-society