



2021

# 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

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 community 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 for World Down Syndrome Day, Run for 3.21, DC Golf Outing, the annual NDSS Gala & Auction and various Team NDSS charity racing events.

## NDSS BOARD OF DIRECTORS

Charles Symington, Chairman	Chris Brooks	Annette Halprin
Tiffany Barfield, Vice Chairman	Megan Burke	Mark Johnson
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	Brandon Gruber	Laurie Walters

## LETTER FROM LEADERSHIP

Dear Friends,

What an incredible year! Through the generosity of our supporters, the National Down Syndrome Society (NDSS) found new and innovative ways to pursue our mission in the face of the COVID-19 pandemic. Despite the many challenges, we tirelessly advocated for the rights of individuals with Down syndrome and their families, and we ensured a steady stream of information and support for our community.

Our 2020-2021 Annual Report provides an overview of our core programs and initiatives and illustrates our impact over the past fiscal year. As the leading human rights organization for all individuals with Down syndrome, NDSS advocated on issues related to the pandemic, as well as those that remain constant in our fight. Our program teams worked with experts and self-advocates to develop much-needed resources and make them available to all. We continued to raise awareness and fight stigma, reaching new audiences of advocates and supporters through innovations in social media. And we engaged our community in even greater numbers through nationwide events that celebrated the many ways individuals with Down syndrome enrich our families and society.

After more than a year of working remotely, gathering virtually and finding new and innovative ways to advocate for and support the Down syndrome community, NDSS is stronger than ever. All of this is possible because of our corporate, foundation and individual supporters.

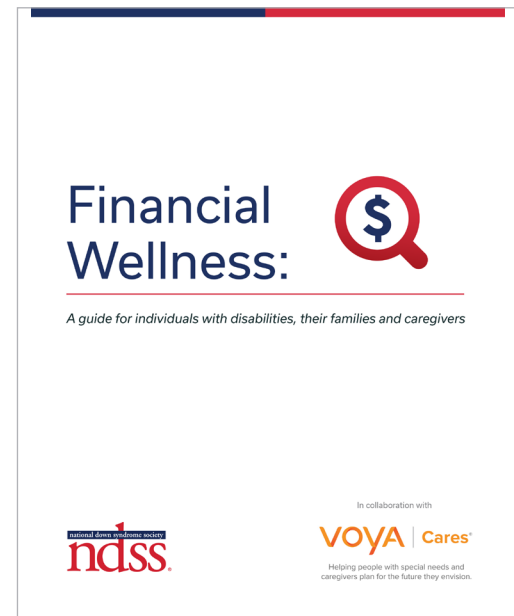
As we look forward, we are grateful to all those who are part of our NDSS family and to those who will join us in the years ahead.

With gratitude,

Kandi Pickard  
President & CEO

Charles Symington  
Chairman

## RESOURCES & SUPPORT



As a critical part of our work to advocate for and support the Down syndrome community, NDSS provides free information, resources and support on topics across the lifespan from birth to end of life through our website, webinars, videos 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 300 local Down syndrome organizations across the country.

During the past year, NDSS has made resources and information available to the community about women's health and hygiene, Down syndrome and Alzheimer's Disease, employment and entrepreneurship, IEPs and distance learning, common medical conditions, financial wellness and more.

### Education

The NDSS Education Program works to develop 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.



### Employment

Through our Employment Program, NDSS seeks to increase access to the workforce for all people with Down syndrome. By collaborating 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 by advocating for public policies that increase access to competitive integrated employment, creating valuable resources, providing technical assistance to corporations, offering local support and training, sharing the success of employees with Down syndrome and promoting entrepreneurship and self-employment opportunities.

### 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 aspect 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. The 2021 Virtual Adult Summit provided the community with live and recorded access to more than 40 presentations by experts and individuals living with Down syndrome. Sessions covered topics such as health and vision care, research, community integration, caregiving, economic self-sufficiency, employment, relationship health and aging.



### COVID-19 Resources

Throughout the last year, NDSS has supported our families by providing updated information, advocacy and tangible support to help them navigate the COVID-19 pandemic including:

- information on COVID-19 and Down syndrome
- advocacy to ensure adults with Down syndrome were prioritized for vaccines
- ride codes from Lyft to help get to vaccine appointments
- resources for navigating education during the pandemic
- advocacy to secure stimulus for adult dependents

## POLICY & ADVOCACY

The National Down Syndrome Society (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 programs, 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.

Like all our work, the NDSS legislative agenda spans the life experience of individuals with Down syndrome from birth through adulthood. It is centered on five important areas: healthcare & research, education, economic self-sufficiency, community integration and employment. These priorities have been shaped by self-advocates, families, affiliate leaders and other stakeholders under the direction of the NDSS Board of Directors and with the advice of the NDSS Public Policy Advisory Committee.

Thanks to the hard work of our grassroots advocates and staff, during the 2021 Fiscal Year:

- dedicated funding was secured to support learning for students with disabilities during the pandemic through the American Rescue Plan
- new organ transplant legislation was passed in ten states: Arkansas, Colorado, Georgia, Minnesota, Montana, North Carolina, Oklahoma, Tennessee, Texas and Wyoming
- new federal legislation, the Charlotte Woodward Organ Transplant Discrimination Prevention Act, was introduced into the 117th Congress, named after NDSS staff member Charlotte Woodward
- federal legislation was reintroduced in the new Congress to phase out subminimum wage, and state legislation was passed in Maine, Minnesota, Hawaii and Washington
- Hudson's Law was passed in Mississippi to ensure all women and families receive the most accurate, up-to-date, evidence-based information about Down syndrome



## COMMUNITY ENGAGEMENT

The Down syndrome community is the heart of NDSS. 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 6,000 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 \$76,000 in grants to 18 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 awards and scholarships possible. Due to COVID-19, the awarding of some of our scholarships was delayed until the Fiscal Year 2022.

#### 2020-2021 O'Neill Tabani Enrichment Fund Recipients

- Kari Balazs
- Madison Best
- Nataleigh Deal
- Emily D'Eugenio
- Matthew Dorsey
- Faith-Christina Duncan
- Hatte Kingston
- Grace McDonald
- Matthew McNeil
- Jacob Stives
- Melissa Walker
- Mary Washam
- BreAnna White
- Tyler Zahos

#### 2020-2021 Dan Piper Award Recipient

- Kyle Koscielniak



### GO ORANGE FOR INCLUSIVE EMPLOYMENT

#### "Go Orange for Employment" Entrepreneurship Grants

In October 2020, NDSS partnered with Voya Cares® to "Go Orange" and boost the national conversation about the need for greater employment opportunities for people with Down syndrome and other disabilities. In celebration of National Disability Employment Awareness Month and Down Syndrome Awareness Month, four entrepreneurs with Down syndrome were awarded grants to invest more capital into their businesses. Ronnie Brown of Fry Guy received a \$25,000 grant, and Julia Tyler of Dance Happy Designs, Joseph Steffy of Poppin Joe's Gourmet Kettle Korn and Nolan Stilwell of Texas Sweet Heat Jam Co. were awarded \$10,000 grants.

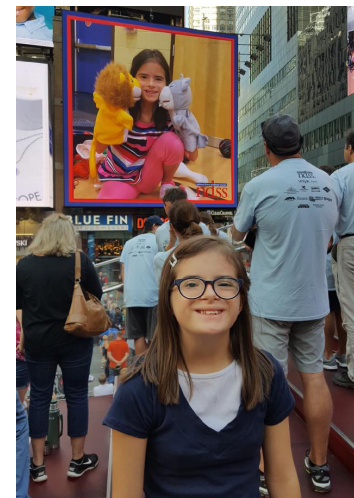


## COMMUNITY ENGAGEMENT (CONTINUED)

### NDSS Events

#### National Buddy Walk® Program

Since 1995, the National Buddy Walk Program has promoted acceptance and inclusion of individuals 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 provided significant challenges for local organizers and many events were cancelled, postponed or took place virtually. Still, nearly 100 local groups found creative ways to celebrate and were supported by NDSS with resources, trainings and waived licensing fees to help them navigate the unprecedented year.



#### 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 12, 2020, thousands of individuals joined us from their homes across the country to view the video presentation and kick off the virtual 2020 New York City Buddy Walk. The live-streamed kick off video featured emcee Chris Wragge from CBS News in NYC, grand marshals Anian Caldwell and Georgie Calles, Dan Piper Award recipient Kyle Koscielniak and more. Throughout the day participants posted photos on social media as they raised awareness and walked in communities throughout the country.

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

On March 21, 2021, our fifth annual Racing for 3.21 on World Down Syndrome Day attracted more than 5000 participants from across the country. This annual virtual event allows participants and advocates to run, walk, bike, hike, swim and/or move for 3.21 miles at any time, any place and at any pace to celebrate and raise awareness for the Down syndrome community on World Down Syndrome Day. In celebration of the 5th anniversary, we offered two new distance options, 32.1 miles and 321 miles. 160 individuals took on the challenge and completed their miles over days or weeks during the month of March.



35th NDSS GALA & AUCTION

#### 35th Annual Gala & Auction

On Thursday March 4, 2021, more than 300 households gathered online to celebrate NDSS and support programs to ensure bright futures for adults with Down syndrome. The event was supported and attended by corporate sponsors, foundations and individuals from across the country. Tom and Rita O'Neill were honored for their decades of work on behalf of the Down syndrome community. Chris Burke joined the event as a special guest, David DeSanctis co-emceed the event with our auctioneer CK Swett and guests were treated to a performance by multiplatinum musical artist Sara Evans.

#### Run for 3.21

Our fourth annual Run for 3.21 took place March 19-21, 2021. The 260 mile adventure started at the United Nations in New York City and finished in Washington, D.C. on the steps of the Lincoln Memorial. Supported by our generous sponsors, the team of 21 runners from around the country participated both on the course and by running in local communities. Together, they raised more than \$100,000 for NDSS programs and completed the relay-style journey in just over 50 hours.



#### NDSS Athlete Ambassador Team

Since launching the NDSS Athlete Ambassador Program in 2017, the team has attracted more than 300 dedicated athletes with and without Down syndrome. The 2020-2021 Athlete Ambassador team included 100 individuals actively involved in sports such as running, swimming, cycling, powerlifting, yoga, boxing, climbing and triathlons. Together, with support from our amazing #TeamNDSS sponsors, they raised more than \$25,000 for NDSS. The program offers various opportunities to foster new relationships and highlight the success of athletes representing NDSS globally.



#### Charity Racing

While many of our traditional races were cancelled due to the pandemic, runners still found ways to participate in our charity racing program and raise awareness and funds for NDSS last year. We had a team of 100 runners participating virtually in the Marine Corps Marathon and runDisney events raising more than \$35,000.

# FINANCIALS

## Statements of Financial Position

	FYE 30-Jun-21	FYE 30-Jun-20	FYE 30-Jun-19 (short year)
<i>Assets</i>	<i>Unaudited</i>	<i>Audited</i>	<i>Reviewed</i>
Cash and cash equivalents	\$1,331,021	\$1,109,813	\$600,866
Contributions receivable	\$46,490	\$47,715	\$97,241
Investments, at fair value	\$13,795,485	\$11,077,616	\$10,648,819
Prepaid expenses and other assets	\$75,052	\$146,797	\$1161,026
Property and equipment, net	\$16,117	\$15,262	\$36,384
<b>TOTAL ASSETS</b>	<b>\$15,264,165</b>	<b>\$12,397,203</b>	<b>\$11,544,336</b>
<i>Liabilities and Net Assets</i>			
<b>LIABILITIES</b>			
Accounts payable and accrued expenses	\$179,446	\$172,028	\$168,704
Note payable - PPP	\$212,805	\$219,087	-
Deferred rent	\$86,264	\$94,245	\$104,085
Deferred revenue	\$67,169	\$168,283	\$97,740
<b>TOTAL LIABILITIES</b>	<b>\$545,684</b>	<b>\$653,643</b>	<b>\$370,529</b>
<b>NET ASSETS</b>			
Without donor restrictons:			
Undesignated	\$3,726,267	\$2,960,664	\$2,630,701
Designated by the Board for endowment	\$9,192,680	\$7,359,839	\$7,031,145
	<b>\$12,918,956</b>	<b>\$10,320,503</b>	<b>\$9,661,846</b>
With donor restrictons:			
Time and purpose restrictions	\$726,084	\$349,616	\$438,520
Endowment fund	\$1,073,441	\$1,073,441	\$1,073,441
	<b>\$1,799,525</b>	<b>\$1,423,057</b>	<b>\$1,511,961</b>
<b>TOTAL NET ASSETS</b>	<b>\$14,718,481</b>	<b>\$11,743,560</b>	<b>\$1,173,807</b>
<b>TOTAL LIABILITIES AND NET ASSETS</b>	<b>\$15,264,165</b>	<b>\$12,397,203</b>	<b>\$11,544,336</b>

## Statements of Activities (With Summarized Comparative Information for FYE 6/30/19 and FYE 6/30/20)

	FYE 6/30/2021				FYE 30-Jun-20	FYE 30-Jun-19 (short year)
	Without Donor Restrictions	Program and Time Restrictions	Endowment Funds	Total	Total	
	<i>Unaudited</i>	<i>Unaudited</i>	<i>Unaudited</i>	<i>Unaudited</i>		<i>Reviewed</i>
<i>Revenue and Other Support</i>						
Contributions	\$1,945,771	\$173,951	-	\$2,119,722	\$1,923,558	\$349,179
National Buddy Walk	-	\$15,267	-	\$15,267	\$377,793	\$36,233
In-kind contributions	\$210,118	-	-	\$210,118	\$227,318	\$8,758
Special events	-	-	-	-	-	-
Less: direct benefit costs	(\$140,945)	-	-	\$415,931	\$370,432	-
PPP Round 1	\$219,087	-	-	\$219,087	-	-
Miscellaneous income	\$15,470	-	-	\$15,470	\$16,097	\$4,661
Net assets released from restrictions	\$154,901	(\$154,901)	-	-	-	-
<b>Total revenue and other support</b>	<b>\$2,961,278</b>	<b>(\$34,317)</b>	<b>-</b>	<b>\$2,995,595</b>	<b>\$2,915,198</b>	<b>\$398,831</b>
<i>Expenses</i>						
Program services						
Public policy	-	-	-	-	\$633,717	\$135,782
Public awareness	-	-	-	-	\$451,321	\$107,801
Buddy Walks	-	-	-	-	\$265,245	\$50,783
Community relations	-	-	-	-	\$788,820	\$450,562
<b>Total program services</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>\$2,139,103</b>	<b>\$744,928</b>
Support services						
Management and general	-	-	-	-	\$250,207	\$59,930
Fundraising	-	-	-	-	\$458,314	\$109,949
<b>Total supporting services</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>\$708,521</b>	<b>\$169,879</b>
<b>Total expenses</b>	<b>\$2,760,364</b>	<b>-</b>	<b>-</b>	<b>\$2,760,364</b>	<b>\$2,847,624</b>	<b>\$914,807</b>
Change in net assets before investment income	\$200,914	\$34,317	-	\$235,231	(\$67,574)	(\$515,976)
Investment income	\$2,397,539	\$342,151	-	\$2,739,690	\$502,179	\$339,588
<b>Change in net assets</b>	<b>\$2,598,453</b>	<b>(\$376,468)</b>	<b>-</b>	<b>\$2,974,921</b>	<b>(\$569,753)</b>	<b>(\$176,388)</b>
Net assets, beginning of year	\$10,320,503	\$349,616	\$1,073,441	\$11,743,560	\$11,173,807	\$11,350,195
<b>Net assets, end of year</b>	<b>\$12,918,956</b>	<b>\$726,084</b>	<b>\$1,073,441</b>	<b>\$14,718,481</b>	<b>\$11,743,560</b>	<b>\$11,173,807</b>









## CONTACT INFORMATION

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## SOCIAL MEDIA

-  Facebook: @NDSS1979
-  Twitter: @NDSS
-  Instagram: @ndssorg
-  YouTube: NDSSorg
-  TikTok: @ndssorg
-  LinkedIn: national-down-syndrome-society