



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



## LETTER FROM LEADERSHIP

Dear Friends,

With the support of our donors, the National Down Syndrome Society (NDSS) makes a profound difference in the lives of individuals with Down syndrome, their families and those who care for them. We are immensely proud of the work of the organization during the 2019-2020 fiscal year, and we are excited to share our accomplishments in this Annual Report. The subsequent pages illustrate the difference our donors' generosity has made over the past year through NDSS programs, resources, advocacy and events.

At the start of the fiscal year, we had a vision for the future of NDSS. This vision included building on our strong, 40-year foundation through greater collaboration with other organizations and by expanding our programs to further support the entire community from diagnosis through end of life. When the COVID-19 pandemic hit, those priorities became even more important.

In the final months of the fiscal year we moved events online, set staff up to work from home and – like many other non-profits – faced uncertainty as we closed out the year and built our budgets and goals for the year ahead. Still, our mission, vision and commitment were unchanged, and we knew the needs of our community were greater than ever.

We quickly reassessed our programs and priorities to respond to the new and changing needs of our families. We took on new legislative initiatives to ensure our community was not forgotten by Congress, and we developed new resources focused on the challenges COVID-19 presented to our community, including collaborating with other Down syndrome organizations on a comprehensive Q&A document. We also reached out to the community and listened to their concerns as we developed materials, trainings and guidance to support them in areas like education, hospitalization, employment and more.

Contributors to NDSS make it possible for us to serve and support our families and local affiliates across the country. We are grateful to each and every individual, family, corporate sponsor, foundation and affiliate who has donated or fundraised to support NDSS this past year. Together, despite the challenges we face, we are making a tangible difference in the lives of our loved ones with Down syndrome.

Thank you for being part of our NDSS family.

With gratitude,

Kandi Pickard  
President & CEO

F. Gordon Spoor  
Chairman

## 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 BOARD OF DIRECTORS

F. Gordon Spoor, CPA, PFS, CGMA, *Chairman*  
Charles Symington, *Vice Chairman*  
Tiffany Barfield, *Secretary*  
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Brandon Gruber  
Annette Halprin  
Mark Johnson  
Sean Duffy  
Heather Lavalley  
Debbie Morris  
Lisa Pelham  
Roger Reeves, PhD  
Brian Rodgers  
Bob Siegel  
CAPT Robert P. Taishoff USN (ret)  
Laurie Walters

## POLICY & ADVOCACY

NDSS' National Advocacy & Public Policy Center (NAPPC) advocates for federal, state and local policies that positively impact people with Down syndrome across the country. Through our grassroots advocacy programs, the NAPPC works with Congress and other federal agencies, as well as state and local officials, to develop and improve laws, regulations and policies supporting people with Down syndrome and their families. NDSS also trains parents, self-advocates and others to advocate on local, state and national levels.

Our comprehensive legislative agenda is centered on five important areas across the lifespan: healthcare & research, education, economic self-sufficiency, community integration and employment. These priorities have been shaped by self-advocates, families, affiliate leaders and others under the direction of the NDSS Board of Directors.

During the 2020 Fiscal Year, NDSS:

- advanced Nondiscrimination in Organ Transplant Discrimination legislation in Indiana, Iowa, Louisiana, Virginia and Washington;
- added 37 Members of Congress as co-sponsors on bills that address NDSS' federal legislative priorities, including 10 new co-sponsors for the Marriage Access for People with Special Abilities Act (MAPSA) (H.R. 1529);



- launched NDSS' first-ever virtual advocacy event, the Buddy Walk® to End #LawSyndrome;
- added seven new Members to the Congressional Task Force on Down Syndrome;
- successfully advocated to ensure people of all ages were included in the Older American's Act Reauthorization, which was signed into law providing caregivers and long-term care services for all individuals with Alzheimer's, including those with Down syndrome.



## COMMUNITY SUPPORT & RESOURCES

NDSS is committed to providing individuals with Down syndrome, their families and the public with information, resources and support. We are proud to work with a network of more than 300 local Down syndrome organizations across the country to support the Down syndrome community. Through our helpline and info email, NDSS answers more than 5,000 requests for information each year, responding to questions from parents, professionals, self-advocates and other interested individuals.

NDSS provides information on a variety of topics related to Down syndrome through our resources and website. We also publish guides and informational brochures in both English and Spanish. Our publications provide comprehensive information across the lifespan of individuals with Down syndrome, from birth to end of life.

### COVID-19 Resources

Beginning in March, NDSS developed a special webpage providing resources and webinars tackling areas of concern for our families, including education, employment and hospitalization. We also worked with a consortium of national Down syndrome organizations to develop a comprehensive Q&A on COVID-19 and Down syndrome. Additionally, we initiated a weekly "coffee chat" social opportunity for self-advocates via videoconference to lessen the social isolation many of them were feeling without the ability to go to school, work or gatherings.



### A Promising Future Together

Our Guide for New and Expectant Parents was updated this year to provide parents who have just received a diagnosis with a comprehensive, up-to-date overview of Down syndrome and critical information on how to support their child.

### 2020 Virtual Adult Summit

As the life expectancy for individuals with Down syndrome continues to increase, 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. Throughout the month of May, our 2020 Virtual Adult Summit incorporated the voices of experts and individuals with Down syndrome. The 65 Virtual Adult Summit sessions provided hundreds of attendees with information on topics such as: saving for the future, mindfulness for caregivers, the role of siblings, regression in adults with Down syndrome and Alzheimer's Disease.



## NDSS SCHOLARSHIPS AND AWARDS

NDSS is proud to offer various scholarships, grants and awards for adults with Down syndrome, including, the O'Neill Tabani Enrichment Fund, the #DSWORKS® Blake Pyron Entrepreneurship Scholarship, the Ethan Saylor Memorial Scholarship, the Brandon Gruber Scholarship and the Dan Piper Award. Each scholarship provides individuals with the opportunity to enhance their lives, whether it be through education, business or getting started on their lifelong dream. This year, thanks to the support of our generous donors and sponsors, NDSS granted \$24,500 to adults with Down syndrome through our scholarships and awards.

The 2019/2020 NDSS Scholarship Recipients were:

### O'Neill Tabani Enrichment Fund

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

### Brandon Gruber Scholarship

- Charlie French
- Bradley Carlisle
- Michelle Roybal

### Dan Piper Award

- Faith-Christina Duncan



## INCLUSIVE EDUCATION

The NDSS Inclusive Education Program works with school districts and families across the nation to create meaningful education experiences for students with Down syndrome. We collaborate with community members and with state and national organizations, legislative leaders and agencies toward positive education outcomes for all students.

Our NDSS Inclusive Education Task Force includes self-advocates, university professors, educational researchers, parents, school administrators, lawyers and inclusive educators from across the country. The Task Force guides our work and helps us provide resources and support to address the needs of students who have Down syndrome, their families and schools.

## INCLUSIVE EMPLOYMENT



Inclusion in the workplace is a cornerstone of independence. However, individuals with Down syndrome do not have the same access to employment as their peers. NDSS is addressing this disparity through ongoing collaboration with businesses, service organizations, government agencies, legislators and other important stakeholders. Our comprehensive approach to promoting employment for individuals with Down syndrome means working to change policy, hiring practices, employment access and public awareness.

### Legislative Agenda

NDSS is working at the state and federal levels to phase out subminimum wage practices. This year, our advocates met with dozens of Congressional offices to push for the Transformation to Competitive Employment Act which resulted in 12 additional cosponsors for this important federal legislation.

### #DSWORKS®

The #DSWORKS® program supports individuals with Down syndrome and collaborates with businesses to increase access to inclusive employment. Over the past year the #DSWORKS® program has hosted more than a dozen webinars and has produced key resources including our COVID-19 Employment Tips. We collaborate with businesses across the country to develop pathways for employment for people with Down syndrome, and the 60+ Success Stories on our website and social media highlight employees with Down syndrome who are advancing their careers.

### CEO Commission for Disability Employment

In 2018, NDSS, the Society for Human Resource Management (SHRM) and Voya Financial founded the CEO Commission for Disability Employment. The Commission raises awareness of the untapped potential of people with disabilities and works to ensure that people with disabilities achieve and maintain equal access to meaningful employment. Understanding the importance of sharing best practices, the CEO Commission for Disability Employment produces monthly education resources which are distributed to leaders in the business community. Each year, new corporations, both large and small, become members of The Commission to support its work and demonstrate their commitment to disability inclusive employment.



Leading the way to an inclusive workforce

## COMMUNITY ENGAGEMENT

### National Buddy Walk® Program

This past year, NDSS was proud to celebrate the 25th Anniversary of the Buddy Walk® Program. The goal of the program is to promote acceptance and inclusion of people with Down syndrome and to raise funds for local and national organizations that support people with Down syndrome and their families. In the fall of 2019, roughly 300,000 people gathered at Buddy Walk® events across the world and raised nearly \$11 million to support programs and initiatives benefitting the Down syndrome community.



### New York City Buddy Walk®

On Saturday, September 14, 2019, the annual Times Square Video kicked off our 2019 New York City Buddy Walk® with photos featuring 500 individuals with Down syndrome. Following the video, more than 2,000 individuals gathered in Central Park to walk, celebrate and help us surpass our fundraising goal, raising more than \$165,000. NDSS was honored to present the 2019 Dan Piper Award to Faith Christina-Duncan. The 2019 Grand Marshals, Nirali Punjya and Hudson Hartman helped make this a memorable event!

### NDSS 3rd Annual DC Golf Outing



On Monday, September 16, 2019, NDSS welcomed more than 60 guests to share a day of golf at the Belle Haven Country Club in Alexandria, VA. At the event, the 2019 Impact Award was presented to The Independent Insurance Agents & Brokers of America (IIABA). The annual Impact Award recognizes groups and individuals who go above and beyond to demonstrate their dedication to NDSS and to making a lasting impact in the lives of those with Down syndrome. The award represents and highlights a commitment to creating long-lasting change and those who strive for all people with Down syndrome to be respected, represented and included. Sponsors and guests generously contributed \$68,000 to support the work of the NDSS National Advocacy & Public Policy Center.

### 34th Annual Gala & Auction

On Thursday, March 5, 2020, the 34th Annual NDSS Gala & Auction in New York City celebrated the theme “Waves of Change.” More than 250 attendees – representing the past, present and future of NDSS – were treated to an evening of entertainment, conversation and celebration. Voya Financial and Voya Cares were honored for their partnership in creating a more inclusive society across employment, economic self-sufficiency and our communities. As a surprise honoree, NDSS honored James Wellman and the Wellman Family, who inspired NDSS' fights against organ transplant discrimination. With the generous support of sponsors and guests, the event raised \$320,000 for NDSS programs and resources.



### Racing for 3.21 on World Down Syndrome Day

On March 21, 2020, NDSS engaged nearly 1300 people in the fourth annual Racing for 3.21 on World Down Syndrome Day. 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. Racing for 3.21 has brought together schools, communities and businesses to promote health and fitness in the Down syndrome community. Due to COVID-19, larger community events were unable to be held, but the event still raised more than \$80,000 and lots of awareness on social media platforms.

### Run for 3.21

Our third annual Run for 3.21 was scheduled for March 19-21, 2020. Due to COVID-19, the event has been moved to a virtual event October 2-4, 2020 for the safety of all our runners and their families. Run for 3.21 is a three-day, 250+ mile adventure. This year it begins in New York City and finishes in Washington, D.C. The event challenges a team of 21 athletes from around the country, supported by our generous sponsors, who work together to raise \$100,000 for NDSS programs and run – nonstop – from the headquarters of the United Nations in New York City to the steps of the United States Capitol. This year, participants will run virtually from their local community while staying connected via video, phone and texts. All 21 runners are still able to participate in some capacity, and everyone is embracing the change and being flexible.

### NDSS Athlete Ambassador Team

Since launching the NDSS Athlete Ambassador Program in 2017, the team has attracted more than 250 dedicated athletes. Among these Athlete Ambassadors are many self-advocates including: Blake Pyron and Charlie French from Texas, Morgan Greer from Tennessee, Joseph Maroukian from Pennsylvania, Jon Stoklosa from Delaware, NDSS Board Member Brandon Gruber from California, Brad Hennefer and AnnaRose Rubright from New Jersey and swimmer Mary Borman from Arkansas. The 2019-2020 Athlete Ambassador team featured 110 individuals actively involved in various sports including running, swimming, cycling, powerlifting, yoga, boxing, climbing and triathlons. Together, with support from our amazing #TeamNDSS sponsors, they raised more than \$35,000 for NDSS. Our Athlete Ambassador Program is growing and offers various opportunities to foster new partnerships and highlight the success of athletes representing NDSS globally.

### Charity Racing

In Fiscal Year 2020, NDSS was a charity partner at several national races including the Marine Corps Marathon, Disney Wine & Dine Half Marathon Weekend presented by Aftershokz, the Walt Disney World Marathon Weekend presented by Cigna, the L.A. Marathon & Big 5K and the Star Wars Rival Run Weekend. In total, 212 charity racing participants raised \$190,000 to support the Down syndrome community.



# FINANCIALS

## Statements of Financial Position

	FYE 30-Jun-20	FYE 30-Jun-19 (short year)	FYE 31-Mar-19
<i>Assets</i>	<i>Audited</i>	<i>Reviewed</i>	<i>Audited</i>
Cash and cash equivalents	\$1,109,813	\$600,866	\$580,586
Contributions receivable	\$47,715	\$97,241	\$198,596
Investments, at fair value	\$11,077,616	\$10,648,819	\$10,959,231
Prepaid expenses and other assets	\$146,797	\$161,026	\$133,241
Property and equipment, net	\$15,262	\$36,384	\$43,321
<b>TOTAL ASSETS</b>	<b>\$12,397,203.00</b>	<b>\$11,544,336</b>	<b>\$11,914,975</b>
<i>Liabilities and Net Assets</i>			
<b>LIABILITIES</b>			
Accounts payable and accrued expenses	\$172,028	\$168,704	\$396,504
Note payable	\$219,087	-	-
Deferred rent	\$94,245	\$104,085	\$105,629
Deferred revenue	\$168,283	\$97,740	\$62,647
<b>TOTAL LIABILITIES</b>	<b>\$653,643</b>	<b>\$370,529</b>	<b>\$564,780</b>
<b>NET ASSETS</b>			
Without donor restrictons:			
Undesignated	\$2,960,664	\$2,630,701	\$2,839,341
Designated by the Board for endowment	\$7,359,839	\$7,031,145	\$7,019,350
	<b>\$10,320,503</b>	<b>\$9,661,846</b>	<b>\$9,858,691</b>
With donor restrictons:			
Time and purpose restrictions	\$349,616	\$438,520	\$418,063
Endowment fund	\$1,073,441	\$1,073,441	\$1,073,441
	<b>\$1,423,057</b>	<b>\$1,511,961</b>	<b>\$1,491,504</b>
<b>TOTAL NET ASSETS</b>	<b>\$11,743,560</b>	<b>\$11,173,807</b>	<b>\$11,350,195</b>
<b>TOTAL LIABILITIES AND NET ASSETS</b>	<b>\$12,397,203</b>	<b>\$11,544,336</b>	<b>\$11,914,975</b>

## Statements of Activities

(With Summarized Comparative Information for FYE 3/31/19 and Short FYE 6/30/19)

	FYE 6/30/2020				FYE 30-Jun-19 (short year)	FYE 31-Mar-19
	Without Donor Restrictions	Program and Time Restrictions	Endowment Funds	Total		
	<i>Audited</i>	<i>Audited</i>	<i>Audited</i>	<i>Audited</i>	<i>Reviewed</i>	<i>Audited</i>
<i>Revenue and Other Support</i>						
Contributions	\$1,766,952	\$156,606	-	\$1,923,558	\$349,179	\$1,580,743
National Buddy Walk	-	\$377,793	-	\$377,793	\$36,233	\$400,617
In-kind contributions	\$227,318	-	-	\$227,318	\$8,758	\$389,315
Special events	-	-	-	-	-	-
Less: direct benefit costs	(\$343,091)	-	-	\$370,432	-	\$250,234
Conference income	-	-	-	-	-	\$12,644
Miscellaneous income	\$16,097	-	-	\$16,097	\$4,661	\$8,481
Net assets released from restrictions	\$695,783	(\$695,783)	-	-	-	-
<b>Total revenue and other support</b>	<b>\$3,076,582</b>	<b>(\$161,384)</b>	<b>-</b>	<b>\$2,915,198</b>	<b>\$398,831</b>	<b>\$2,642,034</b>
<i>Expenses</i>						
Program services						
Public policy	\$633,717	-	-	\$633,719	\$135,782	\$794,379
Public awareness	\$451,321	-	-	\$451,321	\$107,801	\$927,156
Buddy Walks	\$265,245	-	-	\$265,245	\$50,783	\$335,845
Community relations	\$788,820	-	-	\$788,823	\$450,562	\$852,374
<b>Total program services</b>	<b>\$2,139,103</b>	<b>-</b>	<b>-</b>	<b>\$2,139,103</b>	<b>\$744,928</b>	<b>\$2,909,754</b>
Support services						
Management and general	\$250,207	-	-	\$250,207	\$59,930	\$194,143
Fundraising	\$458,314	-	-	\$458,314	\$109,949	\$465,080
<b>Total supporting services</b>	<b>\$708,521</b>	<b>-</b>	<b>-</b>	<b>\$708,521</b>	<b>\$169,879</b>	<b>\$659,223</b>
<b>Total expenses</b>	<b>\$2,847,624</b>	<b>-</b>	<b>-</b>	<b>\$2,847,624</b>	<b>\$914,807</b>	<b>\$3,568,977</b>
Change in net assets before investment income	\$228,958	(\$161,384)	-	\$67,574	(\$515,976)	(\$926,943)
Investment income	\$429,699	\$72,480	-	\$502,179	\$339,588	\$392,518
<b>Change in net assets</b>	<b>\$658,657</b>	<b>(\$88,904)</b>	<b>-</b>	<b>\$569,753</b>	<b>(\$176,388)</b>	<b>(\$534,425)</b>
Net assets, beginning of year	\$9,661,846	\$438,520	\$1,073,441	\$11,173,807	\$11,350,195	\$11,884,620
<b>Net assets, end of year</b>	<b>\$10,320,503</b>	<b>\$349,616</b>	<b>\$1,073,441</b>	<b>\$11,743,560</b>	<b>\$11,173,807</b>	<b>\$11,350,195</b>



## CONTACT INFORMATION

National Down Syndrome Society Headquarters  
8 E 41st Street  
8th Floor  
New York, NY 10017

800-221-4602  
info@ndss.org  
www.ndss.org

## SOCIAL MEDIA

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