

national down syndrome society

1  
ndss®

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



2019  
Annual Report

## CONTENTS

NDSS Mission & Vision Statements ..... 3

Advocacy & Public Policy ..... 4

DS-AMBASSADOR® Program ..... 6

Inclusive Education Program ..... 7

Buddy Walk® on Washington ..... 8

Buddy Walk® & NYC Buddy Walk® ..... 9

#DSWORKS® ..... 10

#DSWORKS® Success Story ..... 10

Community Outreach & Support ..... 12

#TeamNDSS & Athlete Ambassadors ..... 14

Special Events ..... 16

Financials ..... 18

NDSS Board & Contact Info ..... Back Cover

### 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.

## ADVOCACY & PUBLIC POLICY

NDSS' National Advocacy & Public Policy Center, located in Washington, D.C., advocates for federal, state and local policies that positively impact all people with Down syndrome across the country. Our comprehensive legislative agenda is centered on five important areas across the lifespan: healthcare & research, education, economic self-sufficiency, community integration, and employment. We focus on legislation that would improve the lives of people with Down syndrome. These priorities have been shaped by self-advocates, families, affiliate leaders and others under the direction of the NDSS Board of Directors.

NDSS is the leading voice for people with Down syndrome in our nation's capital and in state capitals across the country. Our NDSS National Advocacy & Public Policy Center:

- Works with Congress, federal departments and federal agencies to develop and advance legislation and improve regulations and other policies supported by its comprehensive legislative agenda
- Train, support and educate self-advocates, parents and others to advocate on the local, state and federal levels to positively impact the lives of people with Down syndrome
- Organizes and participates in national and state coalitions that support and help advance the Down syndrome legislative agenda in Washington, D.C.
- Leads the only state-of-the-art national and statewide advocacy program for the Down syndrome community

As the leading human rights organization for all individuals with Down syndrome, NDSS wants to ensure advocates across the country understand advocacy and how to get involved. NDSS leads an advocacy program which includes our NDSS DS-AMBASSADOR® Program, as well as our annual NDSS Buddy Walk® on Washington.

This year, NDSS' federal advocacy and policy priorities were advanced, including the passage of:

- ACE Kids Act - The ACE Kids Act will improve the process by which children with Down syndrome who participate in the Medicaid program, and who also have other complex medical conditions, are able to obtain quality care and coordinated treatments.

At the state level, a number of priorities were also advanced, including:

- Organ transplant discrimination legislation:
  - Washington
  - Louisiana

We also worked to advance organ transplant discrimination legislation in:

- New York
- Subminimum wage
  - Reno, Nevada
  - Seattle, Washington
  - Texas- This legislation prohibits state contractors from paying below minimum wage to people with disabilities

We also worked to advance subminimum wage legislation in the following states:

- Hawaii
- Illinois
- Kentucky
- Nevada
- Oregon
- Texas
- Washington
- West Virginia

## NDSS' End #LawSyndrome Campaign

In October 2017, NDSS launched a campaign to “End #LawSyndrome”. #LawSyndrome addresses the challenges people with Down syndrome confront when they want to follow their career dreams, get married and live independent, productive lives, but face jeopardizing the critical government supports they rely on heavily, such as health care. Outdated laws discourage all people with Down syndrome from fulfilling their potential.

As part of the efforts to End #LawSyndrome, below is a list of short- and long-term legislative priorities:

- Transformation to Competitive Employment Act (H.R. 873/S. 260): The goal of the bill is to increase disability employment through expanding the infrastructure for providing services for competitive integrated employment and integrated services, while simultaneously phasing out Special Wage Certificates (SWCs) under Section 14(c) of the Fair Labor Standards Act.
- The Marriage Access for People with Special Abilities (MAPSA) Act (H.R. 1529): This legislation clarifies that SSI benefits for an individual with an intellectual or developmental disability (ID/DD) will not be affected by marital status. When determining SSI benefits for an individual with ID/DD, only their income and resources will be reviewed, and will not include those of their spouse.



NDSS will also work with Congress to introduce future legislation that:

- Raises income limitations for Medicaid beneficiaries with Down syndrome and other disabilities who are employed
- Creates another category of Medicaid beneficiaries to include those with disabilities who exceed income limitations
- Expands existing Medicaid Buy-In programs for every state
- Makes Home and Community-Based Services mandatory in every state Medicaid program
- Allows individuals with Down syndrome and other disabilities to get married without a decrease in their benefits
- Creates a Trial Work Period program similar to the one for SSDI beneficiaries for SSI beneficiaries
- Offers tax incentives for businesses to hire people with Down syndrome and other intellectual disabilities and provide them with a competitive wage and health benefits



## DS-AMBASSADOR® PROGRAM

Participants in the NDSS DS-AMBASSADOR® Program are volunteer advocates of all abilities committed to taking part in the democratic process and serving as liaisons between NDSS and their congressional delegates. The overarching goal of the NDSS DS-AMBASSADOR® Program is to build long-lasting relationships with U.S. Senators and Representatives to continually raise awareness, educate and advocate for public policy solutions that benefit the Down syndrome community at the federal level. Participants in the program are crucial to the success of NDSS.

The program was revamped at the beginning of 2019 to include a two year contract and commitment from each NDSS DS-AMBASSADOR® and the program has grown to about 200 participants.

Key objectives of the NDSS DS-AMBASSADOR® Program include:

- Strengthen and organize the Down syndrome community's grassroots advocacy network across the nation
- Be more effective on Capitol Hill by building relationships in Washington, DC with Members of Congress and staff
- Engage more affiliates and advocates to provide valued input and feedback to NDSS
- Encourage more advocates to become active in supporting legislative efforts that are beneficial to the Down syndrome community
- Grow the NDSS DS-AMBASSADOR® Program to 435 participants – one for each congressional district in the county

"I am a proud member of the National Down Syndrome Society's Ambassador program under the leadership of Nicole Patton. One of the many things I enjoy most about this program is that I am kept up to date on the latest issues affecting the Down syndrome populations. During our monthly calls I am able to learn about what is taking place across our nation in other communities. Nicole is excellent at facilitating a friendly and engaging meeting while making others feel heard and important. The action alerts that are sent out make it completely effortless to reach out to legislators. I have learned so much about advocacy during my time as a member of this program."

**-Emily Mondschein, DS-AMBASSADOR®, New York**

"The past few years serving as an NDSS DS- Ambassador has proven to be extremely rewarding and humbling experience. NDSS provides detailed and easy to communicate information on current legislation. The experience of working with now retired Rep Bob Goodlatte on legislation like the ABLE Act and Kevin and Avonte's Law was an example of how important the role of self advocates and parent advocates are to the success of the mission of NDSS. I am looking forward to continuing that relationship with our new House Rep Ben Cline."

**-Bill Lawfield, DS-AMBASSADOR®, Virginia**



## INCLUSIVE EDUCATION PROGRAM

NDSS' Inclusive Education Program works alongside families, school districts, and policy makers to ensure that every student with Down syndrome is educated in an inclusive environment. While no two students are alike in skills and talents, each and every student has the right to be a fully accepted and active member of their school participating along with their peers without disabilities in all the activities, instructional and non-instructional, matching their talents with appropriate supports to help them reach their full potential.

Key features of NDSS' Inclusive Education Program include:

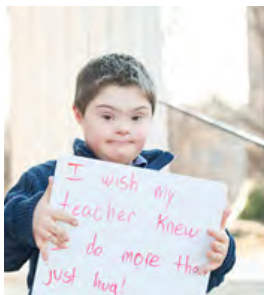
- National Inclusive Education Task Force comprised of world renowned educational researchers, university professors, inclusive educators, inclusive school administrators, lawyers, parents, and self-advocates
- Participating and advocating within the Individualize Education Plan (IEP) process
- Work alongside teachers, principals, and school district administrators to implement best educational and instructional practices
- Work with Congress, federal departments and agencies to develop and advance legislation and improve regulations which allow access to inclusive education for all students

"Sara Jo is amazing! Our family has been struggling with our school district to provide a more inclusive education for our daughter. I reached out to NDSS hoping to get advice or information about how to better advocate for inclusion for my daughter, and we got something so much greater – we got Sara Jo! She came to my daughter's IEP meeting and helped advocate for my daughter to get a solid IEP. We have a long way to go to get our district to embrace full inclusion, but thanks to Sara Jo and her presence at our meeting, we were able to achieve a better IEP than we anticipated. Her support, knowledge, passion and collaborative attitude helped us so much. Thank you NDSS and thank you Sara Jo. Please don't ever stop the amazing work you do helping families like us and our kiddos!

**-Liz Osterhues**

"Our family is so grateful to have stumbled upon a post about the Inclusion Program with NDSS on the Inclusion for Children with Down Syndrome Facebook page in 2018. Prior to this time, we had struggled to get our school districts to see not only that inclusion is best practice for ALL children with special needs, and has been for over 40 years, but also the value it adds to the school community and district at large. Sara Jo has helped us navigate the daunting world of IEP's, and was even present at our daughter's most recent Transition to High School IEP, where she provided the team with great insight and hope for our daughter's academic future. As a result of her presence at this meeting, she was hired by our district to provide inclusion consultation services for the upcoming school year, which we are so excited about!!! We have no doubt that Sara Jo's expertise will prove valuable in ensuring our daughter is afforded a proper inclusive education in high school and beyond. The stars are the limit for our 14 yo, who sadly was in a self contained classroom for much of her academic career against our wishes. She has already shown tremendous growth in an inclusive environment for the past 3 years, and we are thrilled to see all that she is able to accomplish given Sara Jo's support. We only wish this program was around when we were fighting for inclusion in our old district 3 years ago. Thank you Sara Jo and NDSS!"

**-Saadia Qureshi**



## NDSS BUDDY WALK® ON WASHINGTON ADVOCACY CONFERENCE

Our NDSS Buddy Walk® on Washington is an annual two-day conference that involves a day of advocacy training and networking followed by a full day of meetings with Members of Congress and a luncheon on Capitol Hill. The Buddy Walk® on Washington was given its name to maintain the message of the National Buddy Walk® Program – to educate, advocate and celebrate Down syndrome.

During the NDSS Buddy Walk® on Washington, participants receive advocacy training and meet with Members of Congress and their staff on Capitol Hill to advance NDSS' legislative agenda across the lifespan of an individual with Down syndrome: healthcare & research, education, economic self-sufficiency, community integration and employment. The experience is perfectly suited for self-advocates, family members, professionals, affiliate leaders and members and anyone else who wants to make a difference for people with Down syndrome. Previous advocacy experience is not required.

"The Buddy Walk® on Washington was an incredible experience and opportunity to create relationships with my legislators and make connections with fellow Down syndrome advocates. You don't have to be an expert on Policy to enjoy the conference; the advocacy training was very educational and provided us the tools and information necessary to present legislation confidently. My life was changed by the Buddy Walk® on Washington— I found my purpose in the Down syndrome community while walking the halls of Capitol Hill!"

**-Shawn Pittman, DS-AMBASSADOR®, Louisiana**

"Going to the Buddy Walk in Washington DC is very exciting and empowering. Several hundred advocates have an important training the day before and we all head to the Capitol the following day to visit our legislators and educate them on our NDSS priorities. Advocates and families are all received with great respect and appreciation for having the commitment to come in person to educate them on important issues which affect those of us with developmental and intellectual disabilities. I feel we are making a difference by inviting legislators to co-sponsor our bills and join the NDSS caucus. Our voices count!!!! Please join us this coming year!"

**-John Anton, DS-AMBASSADOR®, Self-Advocate, Massachusetts**

"I love advocating for people with Down Syndrome! This year I met with my California representatives in D.C. to talk about Transformation to Competitive Employment Act. I am proud that Senator Harris and Representative Cisneros both supported the bill after our meetings!"

**-Olivia Adams-Falconer, Self-Advocate, California**

### Champions of Change Awards

At the Buddy Walk® on Washington, NDSS also presents our annual Champion of Change Awards to Members of Congress, self-advocates and community leaders who are making a difference in the lives of people with Down syndrome.

The 2019 Champions of Change were:

- Bill Lawfield, DS-AMBASSADOR® of the Year
- Debbie Revels, DS-AMBASSADOR® of the Year
- Lyft, Organization of the Year
- Lowcountry Buddy Walk®, Buddy Walk® of the Year
- Kim Owens, Individual Leader of the Year
- Kate Bartlett, Individual Leader of the Year
- Jadene Ransdell, Stephen Beck Jr. Advocate of the Year
- Frank Stephens, Stephen Beck Jr. Advocate of the Year



## NDSS NATIONAL BUDDY WALK® PROGRAM

Since 1995, the Buddy Walk® has been the premier Down syndrome awareness and advocacy peer-to-peer fundraising program in the world. The Buddy Walk® was created by NDSS to promote acceptance and inclusion of people with Down syndrome and to raise funds for local and national initiatives that support people with Down syndrome and their families. The National Buddy Walk® Program will celebrate its 25th Anniversary in 2019 and introduce a rebrand of the entire program.

2018 Buddy Walk® Accomplishments:

- 220 Walks around the world with international Walks in Canada, Japan, Trinidad & Tobago, Albania, Bermuda and Ghana
- More than 300,000 participants worldwide and nearly \$12 million raised
- New logo and branding roll out finalized for 2019
- All new handbooks and video trainings created for Buddy Walk® Organizers



### 2018 NEW YORK CITY BUDDY WALK®

NDSS hosted its 24th annual flagship New York City Buddy Walk® at The Great Hill in Central Park on Sept. 15, 2018 with almost 2,000 participants.

NDSS kicked off the event by featuring more than 500 individuals with Down syndrome in the highly anticipated Times Square video. The Walk in Central Park was proud to host the 2018 Geber Spokesbaby, Lucas Warren, as Grand Marshal! We also were proud to honor Collette Divito of Collette's Cookies and Mitchel Levitz as our two other Grand Marshals. The Dan Piper Award was established to commemorate Self-Advocate Dan Piper's life by celebrating an individual with Down syndrome- 18 or older-who, through everyday activities, brings about a greater public awareness and understanding of people with Down syndrome in his or her community. NDSS presented the 2018 Dan Piper Award to Benjamin Pelham and the team excited to see who this prestigious award will go to next!



## #DSWORKS® EMPLOYMENT PROGRAM

#DSWORKS® encourages businesses, from Main Street to Wall Street, to invest in hiring individuals with Down syndrome. In addition to employment, NDSS works with our #DSWORKS® Corporate & Strategic partners to create meaningful employment pathways for the Down syndrome community, increasing their bottom line and creating a culture of awareness and inclusion.



### Employment Resources

NDSS maintains a comprehensive repository of employment resources for those interested and involved in the employment process. Our end users include, but are not limited to employers, self-advocates and families. #DSWORKS® streamlines their opportunities with resources to provide support in the onboarding and employment process. Our NDSS #DSWORKS® resources, available in print and online formats, focus on offering a wide variety of information to help educate stakeholders on key aspects of employment including our "NDSS Employer Guide: Valued, Able & Ready to Work: Employing Individuals with Down syndrome."

### Legislative Agenda

#DSWORKS® works closely on legislative agendas with our National Policy & Advocacy center, specifically working to END #lawysndrome. Working on federal and state legislation to support employment opportunities, equal compensation, and fair wages for people with Down syndrome. NDSS is currently advocating for federal legislation and state legislation for Employment First policies, the elimination of subminimum wage and the expansion of financial literacy and options for people with Down syndrome.

### #DSWORKS® Employer Roundtable Partnerships

NDSS' Employer Roundtable events engage with businesses in communities across the country, engaging business leaders, elected officials, and the Down syndrome community. Customizable, Employer Roundtables work to raise awareness within communities about various disability employment efforts. NDSS is proud to be working with many like-minded businesses, among them: Voya Financial, Blake's Snow Shack, Alix Partners, Fiserv, John's Crazy Socks, Bimbo Bakeries, and more.

## #DSWORKS® PROGRAM SUCCESS STORY

### JEFFREY RESNICK & MAX RUBIN

Our ongoing partnership with Saatchi & Saatchi New York (SSNY), we have grown the #DSWORKS® program. With the faith in our program and most importantly the Down syndrome community, SSNY offered one of their coveted internship opportunities to two self-advocates in back to back summers.

In the summer of 2018, Jeffrey Resnick worked as a Production Assistant for SSNY in New York City as part of their Summer Internship program. Jeffrey was an integral part of the intern class, supporting their summer leadership projects, and promoting projects to the SSNY senior leadership team. Jeffrey's success at SSNY led him to be featured in the NDSS 40th Anniversary Video, honoring his 10+ year relationship with his girlfriend.

To continue the partnership and internship program, SSNY extended another coveted position in their internship program to a young man, Max Rubin in the summer of 2019. Max, a student at Cape Cod Community College in the Project Forward Project also works with the production team at SSNY.

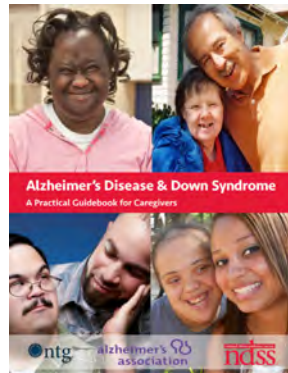
#DSWORKS® Success stories continue to grow with ongoing support of our Strategic Partners, national affiliates, and entrepreneurs across the country.

## NDSS DOWN SYNDROME COMMUNITY OUTREACH & SUPPORT

NDSS is proud to work with a network of more than 380 local Down syndrome affiliates across the country to provide an array of benefits to help better service the Down syndrome community.

Through our Information and Referral Center, NDSS receives more than 10,000 requests a year for information on Down syndrome. NDSS responds to questions from parents, professionals, self-advocates and other interested individuals. Our toll-free helpline and email service is supported by a translation service that can be accessed in more than 150 languages.

NDSS continues to provide the most up to date information on Down syndrome. NDSS publishes guides and information 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.



### Alzheimer's Disease and Down Syndrome: A Practical Guide for Caregivers

NDSS' most recent publication: "Alzheimer's Disease and Down Syndrome: A Practical Guide for Caregivers" is available in English, Spanish and French for our community.

This guide was written to help empower families and caregivers with knowledge about the connection between Down syndrome and Alzheimer's disease, suggestions about how to carefully and thoughtfully evaluate changes that may be observed with aging, and guidance about how to adapt and thrive within an ever-changing caregiving role when a diagnosis is made.

### NDSS Annual Down Syndrome Adult Summit

During the past few years, the NDSS Information and Referral Center has received an increase in requests for support and information on aging, Alzheimer's disease and end of life care. The demand for information has led NDSS to invest in the adult space to provide critical information for self-advocates, families, friends, caregivers and professionals — and thus the NDSS Down Syndrome Adult Summit was created. 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 throughout adulthood.



### NDSS Scholarship Programs

NDSS is proud to offer various scholarships and grants for self-advocates, including, the O'Neill Tabani Enrichment Fund (OTEF), the #DSWORKS® Blake Pyron Entrepreneurship Scholarship, the Ethan Saylor Memorial Scholarship and the Brandon Gruber Scholarship. Each scholarship provides individuals with the opportunity to enhance their lives, whether it be through education, business or getting started on their lifelong dream.

The 2019 NDSS Scholarship Recipients are:

#### **OTEF:**

Mary Borman  
 Jabriel Deluna  
 Hannah LaCour  
 Mathew Strachan  
 Megan Caldwell  
 Brittany Kennedy  
 Kiernan Treptow  
 Leah Godaire  
 Rachel Handlin  
 Thomas Pratt  
 Kathleen Spadaro  
 Dalton Cron  
 Chelsea Bailey  
 Jonny Peay  
 Kevin Davis  
 Jack McCabe

#### **#DSWORKS® Blake Pyron Entrepreneurship Scholarship:**

Faith-Christina Duncan

#### **Ethan Saylor Memorial Scholarship**

Matt McNeil

#### **Brandon Gruber Scholarship**

Madison Best  
 Adam DeBacker  
 Rachel Handlin

#### **Dan Piper Award**

Benjamin Pelham



## NDSS ATHLETE AMBASSADOR PROGRAM

Since launching the NDSS Athlete Ambassador Program in 2017, the team has attracted nearly 200 dedicated Athletes. Among these Athletes are many self-advocates including: Blake Pyron & Kayleigh Williamson from Texas, 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, just to name a few. The 2018-2019 Athlete Ambassador team featured individuals who are active in a variety of sports such as running, swimming, cycling, powerlifting, yoga, climbing, and triathlons. Our athletes push themselves in training and competition to be the best they can be while representing and advocating for the Down syndrome community. Whether it's a local 5k or an international Ironman race, our athletes can be found across the globe competing for NDSS.

This program has allowed NDSS to secure incredible sports-focused partnerships, including Newton Running, Honeystinger, Zensah, Flipbelt, Headsweats, Bombas, Nuun, RunLites, NoxGear, Foxelli Headlamps, Defunkify Detergent, Running Warehouse and Road ID, that have helped make all #TeamNDSS events possible over the past year.

Our Athlete Ambassador Program is growing, and offers various opportunities to foster new partnerships and highlight the success of athletes representing NDSS globally through various sports and activities.



### Run for 3.21 on World Down Syndrome Day

Our second annual Run for 3.21 was held March 19-21, 2019. Run for 3.21 is a three-day, 250+ mile adventure from Washington, D.C. to New York City. The event brings together a team of 21 athletes from around the country working together to run – nonstop – from the steps of the United States Capitol to the headquarters of the United Nations in New York City. This year, we made a last minute change to our route, when we received word the TODAY Show wanted to broadcast our runners live on television crossing the finish line. On March 21, 2019, World Down Syndrome Day, our team of runners ran through Rockefeller Plaza and were greeted by Savannah Guthrie and the Today Show team. Runner and Mom, Jaime Zambelli was interviewed by Savannah and showcased the NDSS mission as the leading human rights organization for all individuals with Down syndrome; the team raised close to \$100,000.00 to support NDSS' mission.

### Racing for 3.21 on World Down Syndrome Day

On March 21, 2019, NDSS welcomed more than 1500 people to the third annual "virtual" Racing for 3.21 on World Down Syndrome Day. This 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 raised over \$263,000.00 the last three years and has brought together schools, communities and businesses to promote health and fitness in the Down syndrome community.

NDSS would like to recognize the 2019 Run for 3.21 Sponsors: Bombas, Delaware Running Company, Goodr, Headsweats, KT Tape, New York Sports Clubs, NoxGear, Philadelphia Sports Clubs, Potomac River Running, Running Warehouse, Voya Financial, WaWa, Wegmans and ZBest Worldwide.



### Charity Racing Teams

In 2018 and 2019, NDSS was a charity partner at several national races including the Marine Corps Marathon, Disney Wine & Dine Half Marathon Weekend presented by MISFIT™, the Walt Disney World Marathon Weekend presented by Cigna, and the Disney Princess Half Marathon weekend presented by Children's Miracle Network®. More than 125 runners participated on behalf of NDSS, raising more than \$115,000.00 for the organization. This coming year, NDSS will bring Charity Racing Teams to the Marine Corps Marathon, the Disney Wine & Dine Half Marathon Weekend presented by MISFIT™, Walt Disney World Marathon Weekend presented by Cigna, the Star Wars™ Rival Run Weekend presented by Otterbox and the L.A. Marathon.



*For more information on our Athlete Ambassador Team and Charity Racing Teams, please contact [teamndss@ndss.org](mailto:teamndss@ndss.org)*



## NDSS AWARENESS & SPECIAL EVENTS

### 22nd Annual NDSS Golf Outing

This year was our 22nd year bringing together a group of dedicated golfers to help raise funds for NDSS. Our 22nd Annual NDSS Golf Outing took place on June 7, 2018, and celebrated the importance of moving past “awareness and acceptance”. What we want is to deliver and make those changes by leading the human rights campaign not only for those with Down syndrome but for those with all disabilities. We’re here to show that life has value, and that people with Down syndrome make this world a better place. Golfers took the course at The Stanwich Club in Greenwich, CT to celebrate continued change and progress within the Down syndrome and disability community.



### NDSS 2nd Annual DC Golf Outing

On October 29, 2018 we welcomed over 60 guests to share the day with us at the Belle Have Country Club in Alexandria, VA for the 2nd Annual DC Golf Outing. Participation in this event is critical for our community and will make it possible for many individuals with Down syndrome to pursue their dreams, find meaningful, competitive employment and improve their lives. This event is one of many that is about Ending #LawSyndrome for all. Law Syndrome is about challenging the norm, and changing a centuries-worth of discriminatory laws that hold back all individuals living with Down syndrome and other disabilities. It is about allowing individuals with Down syndrome to plan for the future, to go to school, to get married, to start a business, to have equal access to healthcare and to pursue the American Dream.

### C21 Pop-up Restaurants

C21 is a pop-up restaurant offering a one-of-a-kind dining experience. Its name refers to the tripled 21st chromosome that causes Down syndrome. This event showcases to the world that individuals with Down syndrome are ready, willing and able to work.

In partnership with Voya Financial, NDSS hosted C21 in New York City, Atlanta and Dallas this year. NDSS also partnered with a local affiliate, the Down Syndrome Association of Greater New Orleans, to host a C21 during the Buddy Walk® Organizers Conference. C21 continues to be of great interests to affiliates across the country and NDSS looks forward to bringing the magic of this event to a city near you.



### NDSS 33rd Annual Gala & Auction—NDSS 40th Anniversary Celebration

On January 24, 2019, the National Down Syndrome Society (NDSS), the leading human rights organization for all individuals with Down syndrome, hosted our 40th Anniversary Gala & Auction at Gotham Hall in New York City. More than 270 supporters joined together to celebrate our NDSS mission, the accomplishments of individuals with Down syndrome and those who contribute to the Down syndrome community.

The night opened with our cocktail reception and silent auction, where guests bet on their favorites of 75 auction items! As the evening progressed, our animated auctioneer, CK Swett, captivated the room for our live auction and raised over \$20,000 while dinner was being served. Finally, we closed out the evening with an after party with a performance by The Mere Mortals. Nancy Newman studio host for the New York Yankees and the Brooklyn Nets pre- and post-game shows served as our master of ceremonies for the evening, and we recognized two incredible honorees for their contributions to the Down syndrome community.

This year, NDSS honored the Professional Baseball Athletic Trainers Society (PBATs) for their work in inclusion, and Promoting a Lifetime of Activity for Youth (PLAY) Campaign. This campaign combats child obesity and promotes healthy living and decision making among young people in America through interaction with Major League Baseball players, trainers and staff. We also paid a surprise tribute to Betsy Goodwin, without whom the progress we have made in the last 40 years would not have been possible. Since 1979, NDSS has been the leading voice in advocating for people with Down syndrome and their families. Furthermore, we are now the largest nonprofit organization dedicated to people with Down syndrome and their families in the United States. Your generosity in support of this gala and all year long allows us to give individuals with Down syndrome, their families and caregivers the support and resources they need to thrive.



### 14th Annual CARING with Congress

The 14th Annual CARING with Congress event took place on Wednesday, July 11, 2018, in Washington, DC. We were joined by Senators, Congressmen and Congresswomen and other supporters on Capitol Hill in Washington, D.C. to raise money for the NDSS Research Innovation & Discovery Fund (RIDF). The Fund supports research and clinical infrastructure needs for the Down syndrome scientific and research community. We raised over \$57,000 for the RIDF thanks to the support of our generous sponsors and donors!

## FINANCIALS

Statements of Financial Position  
March 31, 2019  
(With Summarized Comparative Information for 2018)

	2019	2018
<b>Assets</b>		
Cash and cash equivalents	\$580,586	\$754,279
Contributions receivable	\$198,596	\$158,226
Investments, at fair value	\$10,959,231	\$11,140,611
Prepaid expenses and other assets	\$133,241	\$136,614
Property and equipment, net	\$43,321	\$67,865
<b>TOTAL ASSETS</b>	<b>\$11,914,975</b>	<b>\$12,257,595</b>
<b>Liabilities and Net Assets</b>		
<b>LIABILITIES</b>		
Accounts payable and accrued expenses	\$396,504	\$253,164
Deferred rent	\$105,629	\$109,875
Deferred revenue	\$62,647	\$9,936
<b>TOTAL LIABILITIES</b>	<b>\$564,780</b>	<b>\$372,975</b>
<b>NET ASSETS</b>		
Without donor restrictions:		
Undesignated	\$2,839,341	\$3,612,902
Designated by the Board for endowment	\$7,019,350	\$6,792,652
	<b>\$9,858,691</b>	<b>\$10,405,554</b>
With donor restrictions:		
Time and purpose restrictions	\$418,063	\$405,625
Endowment fund	\$1,073,441	\$1,073,441
<b>TOTAL NET ASSETS</b>	<b>\$11,350,195</b>	<b>\$11,884,620</b>
<b>TOTAL LIABILITIES AND NET ASSETS</b>	<b>\$11,914,975</b>	<b>\$12,257,595</b>

Statements of Activities  
Year Ended March 31, 2019  
(With Summarized Comparative Information for 2018)

	With Donor Restrictions			Total	
	Without Donor Restrictions	Program and Time Restrictions	Endowment Funds	2019	2018
<b>Revenue and Other Support</b>					
Contributions	\$1,347,687	\$233,056	-	\$1,580,743	\$1,966,435
National Buddy Walk	-	\$400,617	-	\$400,617	\$419,790
In-kind contributions	\$389,315	-	-	\$389,315	\$792,637
Special events			\$659,837		
Less: direct benefit costs	(\$409,603)	-	-	\$250,234	\$387,616
Conference income	\$12,644	-	-	\$12,644	\$35,911
Miscellaneous income	\$8,481	-	-	\$8,481	\$32,013
Net assets released from restrictions	\$621,235	(\$621,235)	-	-	-
<b>Total revenue and other support</b>	<b>\$2,629,596</b>	<b>\$12,438</b>	<b>-</b>	<b>\$2,642,034</b>	<b>\$3,634,402</b>
<b>Expenses</b>					
Program services					
Public policy	\$794,379	-	-	\$794,379	\$401,621
Public awareness	\$927,156	-	-	\$927,156	\$1,960,055
Buddy Walks	\$335,845	-	-	\$335,845	\$284,759
Community relations	\$852,374	-	-	\$852,374	\$853,028
<b>Total program services</b>	<b>\$2,909,754</b>	<b>-</b>	<b>-</b>	<b>\$2,909,754</b>	<b>\$3,499,463</b>
Support services					
Management and general	\$194,143	-	-	\$194,143	\$326,168
Fundraising	\$465,080	-	-	\$465,080	\$681,030
<b>Total supporting services</b>	<b>\$659,223</b>	<b>-</b>	<b>-</b>	<b>\$659,223</b>	<b>\$1,007,198</b>
<b>Total expenses</b>	<b>\$3,568,977</b>	<b>-</b>	<b>-</b>	<b>\$3,568,977</b>	<b>\$4,506,661</b>
Change in net assets before investment income	(\$939,381)	\$12,438	-	(\$926,943)	(\$872,259)
Investment income	\$392,518	-	-	\$392,518	\$895,889
<b>Change in net assets</b>	<b>(\$546,863)</b>	<b>\$12,438</b>	<b>-</b>	<b>(\$534,425)</b>	<b>\$23,630</b>
Net assets, beginning of year	\$10,405,554	\$405,625	\$1,073,441	\$11,884,620	\$11,860,990
<b>Net assets, end of year</b>	<b>\$9,858,691</b>	<b>\$418,063</b>	<b>\$1,073,441</b>	<b>\$11,350,195</b>	<b>\$11,884,620</b>



## NDSS BOARD

Gordon Spoor, CPA, PFS, CGMA, Chairman

Charles Symington, Vice Chairman

Tiffany Barfield, Secretary

Carlo P. Frappolli, Treasurer

CAPT Robert P. Taishoff USN (ret), Past Chairman

Elizabeth F. Goodwin, Founder

Amy G. Allyn

Chris Brooks

John Cronin

Janet Slaughter Eissenstat

Steve Freeman

Sean Fromm

Anthony (Tony) J. Gostkowski

Brandon Gruber

Annette Halprin

Mark Johnson

Rick Kosmalski

Heather Lavallee

Debbie Morris

Megan Perez

Roger Reeves, PhD

Brian Rodgers

Bob Seigel

Laurie Walters



## CONTACT INFORMATION

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

NDSS National Advocacy & Public Policy Center  
1100 H Street, NW  
Suite 1030  
Washington, DC 20005

## SOCIAL MEDIA

 Facebook: @NDSS1979

 Twitter: @NDSS

 Instagram: @ndssorg

 YouTube: NDSSorg