

national down syndrome society

ndss[®]

2018 Annual Report

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



MARCH 22, 2018

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NDSS Advocates & Friends:

As another year has come and gone, we take this time to reflect on the many achievements accomplished by the National Down Syndrome Society (NDSS) advocates, supporters, ambassadors and staff. We are pleased to share with you our 2018 Annual Report, highlighting activities from April 1, 2017 through March 31, 2018.

For nearly 40 years, NDSS has been the leading voice and organization for the Down syndrome community in the United States. We pride ourselves on being an organization that represents the interests of all individuals with Down syndrome across the lifespan and across all areas, including healthcare and research, inclusive education, employment, community integration and economic self-sufficiency.

In this report, we'll highlight the successes across our four program areas – The National Advocacy & Policy Center, our National Inclusive Health & Sport Program including the National Buddy Walk®, our Community Outreach & Support and the #DSWORKS® Employment Program – plus our public awareness initiatives, national, state and local outreach and our NDSS special events.

In October, we hosted our first-ever NDSS Leadership Summit, in conjunction with the Lincoln Leadership Institute, which brought affiliate leaders, self-advocates and their families from across the country to our nation's capital. The summit proved to be a successful event in better understanding how NDSS can continue to serve our self-advocates and fulfill our mission. At the end of the summit, we hosted our first C21 pop-up restaurant on Capitol Hill and concluded the evening by launching the latest NDSS campaign – End #LawSyndrome.

Several of our most notable achievements of the past year include:

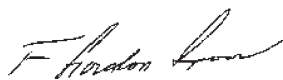
- Launched a new #DSWORKS® partnership with Voya Cares to show the world that people with Down syndrome, from Main Street to Wall Street, are ready, willing and ABLE to work.
- Led the advocacy effort, as part of our End #LawSyndrome Campaign, to pass the ABLE to Work Act, which improves upon the landmark Stephen Beck Jr., ABLE Act (Public Law 113-295) to allow individuals with disabilities who are working to contribute their paychecks to an ABLE Account (beyond what a family can give on an annual basis).
- Hosted a historic, first of its kind 250-mile run from the steps of the U.S. Capitol to the headquarters of the United Nations on World Down Syndrome Day to educate, advocate and celebrate Down syndrome.
- Joined the Professional Baseball Athletic Trainers Society® (PBATS) as the disability partner for Major League Baseball's (MLB) Promoting a Lifetime of Activity for Youth (PLAY) Campaign to promote and encourage inclusive and healthy lifestyles for individuals with Down syndrome and other disabilities.

None of this would have been possible without the continued support of NDSS' generous donors and supporters as well as the commitment of our dedicated and passionate NDSS staff and board of directors. As we move forward in 2019 and beyond, we invite you to join us on this journey of advocacy and activism.

Onward and upward,



Sara Hart Weir, MS
President



F. Gordon Spoor
Chairman

About the National Down Syndrome Society

The National Down Syndrome Society (NDSS), established in 1979, is the leading human rights organization for all individuals with Down syndrome. At NDSS, we envision 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 has four cutting-edge, state-of-the-art programmatic pillars that support our platform as the largest nonprofit organization in the nation representing people with Down syndrome and their families. These programmatic pillars include the following:

- National Advocacy & Public Policy Center
- National Inclusive Health & Sport Program including the National Buddy Walk®
- #DSWORKS® Employment Program
- Down Syndrome Community Outreach & Support

NDSS has worked for nearly 40 years to support people with Down syndrome and their families through national leadership in education, research and advocacy. NDSS was founded by Elizabeth (Betsy) Goodwin, following the birth of her daughter, Carson, who happens to have Down syndrome. After Carson's birth, Elizabeth and her husband, Barton, soon discovered that support and resources available to parents of a child with Down syndrome were very limited. Betsy began collaborating with her close friend, Arden Moulton, and in 1979, NDSS gained official nonprofit status.

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.

"The advocacy of NDSS has given promise to Gina's future by providing opportunities to help her realize her potential and become a valued member of her community. Our family will continue to support the mission of NDSS to ensure that all individuals with Down syndrome are able to live their dreams!"

- Liz Baldini



National NDSS Advocacy & Public Policy Center

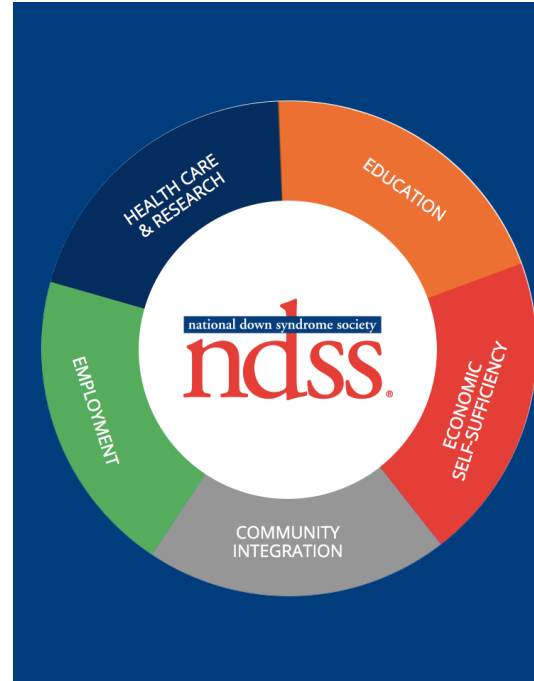


NDSS' National Advocacy & Public Policy Center, located in Washington, D.C., advocates for federal, state and local policies that positively impact all people with Down syndrome across the country. Our comprehensive legislative agenda is centered on five important areas across the lifespan: healthcare & 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
- Trains, supports and educates 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.



**DOWN SYNDROME NEVER STOPPED US.
LAW SYNDROME IS HOLDING US BACK.**

END LAW SYNDROME
TEXT LAW SYNDROME TO 52006



This year, a number of NDSS' federal advocacy and policy priorities were advanced, including:

- ABLÉ to Work and ABLÉ Financial Planning were passed
- A new trans-NIH research initiative, named the NIH INCLUDE Project, on critical health and quality-of-life needs for individuals with Down syndrome, will include \$21 million dedicated by NIH for Down syndrome research in FY2018 and an estimated \$58 million in FY2019 and beyond
- Kevin & Avonte's Law, which enhances the safety of individuals with Down syndrome who wander and provide peace of mind to their families. It also provides much-needed support and resources (\$2 million in total) to law enforcement agencies to develop programs and assist in locating missing persons
- Government Accountability Office study on the use of seclusion and restrains
- \$3 million to community development financial institutions to support access to ABLÉ accounts

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

- **Organ transplant discrimination legislation in**
 - Kansas ◦ Delaware ◦ Oregon
- **Subminimum wage**
 - Alaska
- **ABLE Programs that have opened this year**

◦ Arizona	◦ Georgia	◦ Missouri	◦ Pennsylvania
◦ Colorado	◦ Indiana	◦ Montana	◦ South Carolina
◦ Delaware	◦ Louisiana	◦ New Hampshire	◦ Wyoming
◦ District of Columbia	◦ Maryland	◦ New Mexico	
	◦ Massachusetts	◦ New York	

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 our efforts to End #LawSyndrome, a bipartisan working group on disability employment was launched to proactively advance critical legislation to allow individuals with Down syndrome and other disabilities to have access to meaningful, competitive employment, without jeopardizing healthcare benefits like Medicaid. This effort is led by Congresswoman Cathy McMorris Rodgers (R-WA), Asst. Democratic Leader Jim Clyburn (D-SC), Congressman Gregg Harper (R-MS), Congressman Joe Crowley (D-NJ) and Congressman Tony Cárdenas (D-CA).

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

- ABLÉ to Work Act ✓
- ABLÉ Financial Planning Act ✓
- Transitioning to Integrated and Meaningful Employment (TIME) Act – Active legislation - would phase out the Fair Labor Standards Act Section 14(c), which authorizes the Secretary of Labor to issue certificates to certain entities, permitting them to pay workers with disabilities subminimum wage, sometimes as little as \$0.30 an hour.

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

NDSS 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.

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, D.C. 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 country





“ The National Down Syndrome Society is an organization that has blessed many families, including my own. The staff is busy everyday meeting with members of the President’s Cabinet, Members of Congress, Governors, State Legislatures, Law Enforcement, Doctors, the United Nations, and representatives from various countries. Their top priority is the personal interactions with people who actually happen to have Down syndrome. NDSS advocates WITH self-advocates. It gives them a seat at the table so they have the opportunity to explain the need for improving their opportunities in work, education, medical opportunities, and social acceptance. NDSS is an organization that spotlights the Human Rights of all people with Down syndrome and works for the Social Justice needed for reform. Lives are benefitting and futures are improving thanks to NDSS. ”

— Steve Slack, West Virginia, 2018 Champion of Change: DS-AMBASSADOR® of the Year

“ Advocating with NDSS is a rewarding experience for me and other ambassadors. It has offered me over the years many opportunities to serve by raising awareness that people with Down syndrome and other disabilities are capable people who merit a chance to demonstrate abilities. Thanks to our joint efforts, especially with #DSWORKS® and the Education Inclusion Task Force, changes are taking place at all levels and having positive impact on both people with and without disabilities. It is making our society a better place for all of us. ” — David Egan, Virginia, DS-AMBASSADOR®

NDSS Buddy Walk® on Washington Advocacy Conference

“Going to Washington DC for the Buddy Walk is something I have done for at least five years. Our senators and congressmen have been very nice and have supported Down syndrome issues. I like to go because when they see me now we are friends. I even worked in my congressman’s office as an intern this summer! I know what I say to them about Down syndrome issues matters a lot and I feel like I am helping all of us with Down syndrome to get support and understanding.” – **Mary Borman, Arkansas, Self-Advocate of the Year**

“The Buddy Walk on Washington gave my family the training and information to be successful advocates. We were able to get our congressman to co-sponsor an important piece of legislation! We will be able to use what we learned to be effective advocates in the future. Thank you for making a difference for my family!” – **Janet Caramello, Florida, CEO/Executive Director of Down Syndrome Association of Central Florida**

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.

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 2018 Champions of Change were:

Debra Alfarone, *Steve Beck Advocate of the Year*

Mary Borman, *Self Advocate of the Year*

David DeSanctis, *Self-Advocate of the Year*

Patricia Ehrle, *NDSS DS-AMBASSADOR® of the Year*

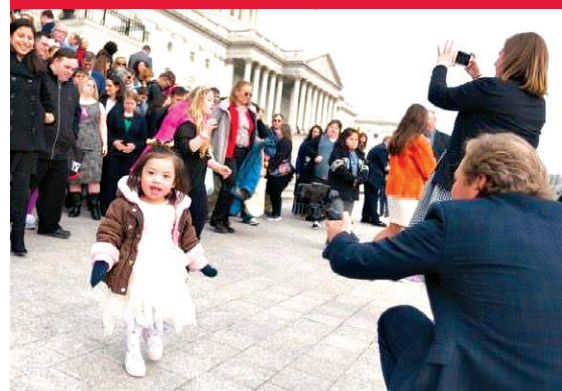
Steve Slack, *NDSS DS-AMBASSADOR® of the Year*

Columbus Buddy Walk, *Buddy Walk® of the Year*

National STABLE Program, *Organization of the Year*

National Inclusive Health & Sport Program

The NDSS Inclusive Health and Sports (IHS) program is our newest initiative dedicated to health, the most important and critical human right. IHS includes our National Buddy Walk® program, the premier advocacy event for Down syndrome in the United States and the world’s most recognized public awareness program for the Down syndrome community, the Athlete Ambassador Program, Charity Racing Teams, and our Healthy Community Programs including Racing for 3.21 on World Down Syndrome Day.



NDSS National Buddy Walk® Program

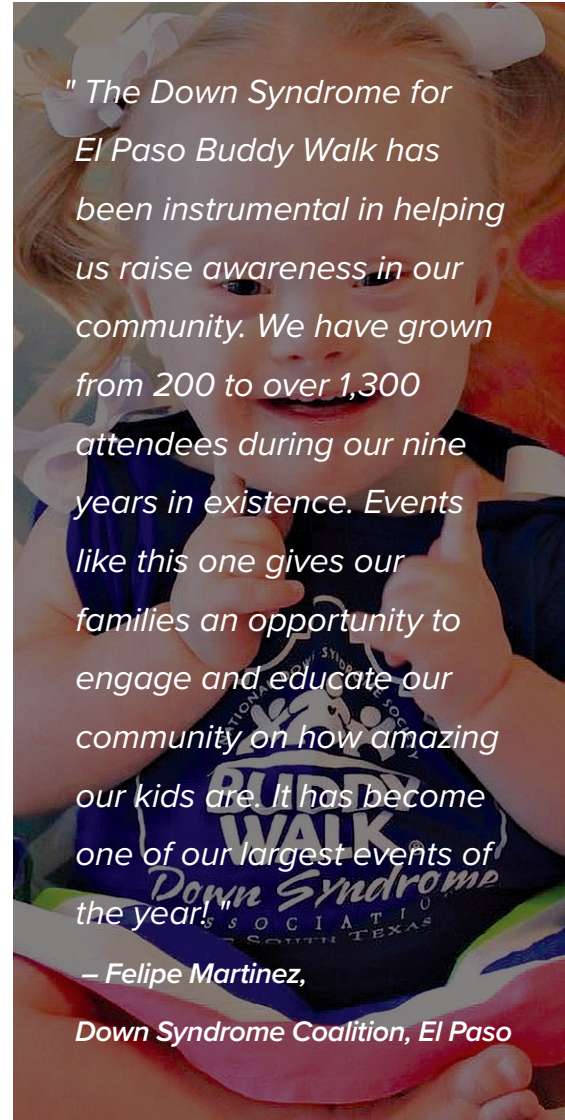
Since 1995, the Buddy Walk® has been the premier Down syndrome awareness and advocacy peer-to-peer fundraising program in the world. The Buddy Walk® was created by NDSS to promote acceptance and inclusion of people with Down syndrome and to raise funds for local and national initiatives that support people with Down syndrome and their families. The National Buddy Walk® Program celebrated its 23rd year in 2017 with many wonderful successes.

2017 Buddy Walk® Accomplishments:

- 231 Walks around the world
- International Walks in Canada, Japan, Albania, Bermuda and New Zealand
- More than 300,000 participants
- Nearly \$12 million raised

“Lowcountry Down Syndrome Society is in the midst of organizing its 13th annual Buddy Walk in Savannah, Georgia’s historic Forsyth Park. The Buddy Walk program lends immediate legitimacy and visibility to our grassroots organization, attracting thousands of families from around our region as well as volunteers, sponsors and other advocates. It is an amazing program that brings our communities together around issues that improve ALL lives. We are so excited for the upcoming 2018 Buddy Walk as Savannah’s first HEALTHY Buddy Walk — addressing issues of healthy lifestyles by initiating relationships with health-focused organizations and vendors that will support our families and organization.” — Tom Kenkel, Lowcountry Down Syndrome Society

“The Buddy Walk program’s meaning for DSAOC is celebration, awareness and unity. The Orange County Buddy Walk has opened the door to many valued relationships with local corporation leaders, and other members in our community who want to learn more and take part in something meaningful. This event also allows DSAOC publicly to show support of our long-standing national organization, NDSS, and it reminds families that we have national organizations pushing for positive change and inclusion for our loved ones with Down syndrome. Thank you, NDSS!” — Kellie Perez, Down Syndrome Association Orange County



“The Down Syndrome for El Paso Buddy Walk has been instrumental in helping us raise awareness in our community. We have grown from 200 to over 1,300 attendees during our nine years in existence. Events like this one gives our families an opportunity to engage and educate our community on how amazing our kids are. It has become one of our largest events of the year!”

— Felipe Martinez,
Down Syndrome Coalition, El Paso



2017 New York City Buddy Walk®

NDSS hosted its 23rd annual flagship New York City Buddy Walk® at The Great Hill in Central Park on Sept. 16, 2017 with more than 2,000 participants.

NDSS kicked off the event by featuring more than 400 individuals with Down syndrome in the highly anticipated Times Square video. The Walk in Central Park included an hour-long dance party, Zumba, sports games, obstacle courses, carnival games, snow cones and unlimited hotdogs and pizza!

NDSS presented the 2017 Dan Piper Award to Brandon Gruber. John Cronin, co-owner of John's Crazy Socks, served as one of our Grand Marshals. At that time, John's Crazy Socks had grown its sock company into a business that brought in more than \$1.4 million in revenue in a little more than a year, all based on a simple mission statement: to spread happiness.



#DSWORKS® Employment Program

Ready, Willing, and ABLE to WORK

#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 careers 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 everyone involved in the employment process including self-advocates, employers, job coaches, professionals, academics and parents. Our NDSS #DSWORKS® webinar series and other resources, such as customized employment plans, all available in print and web-based, 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

NDSS is advancing a comprehensive federal and state legislation agenda that breaks down archaic legislative barriers to employment, supports equal compensation and fair wages for people with Down syndrome and creates incentives to hire individuals with Down syndrome across all types of employers. NDSS is currently advocating for federal legislation like the TIME Act and state legislation like 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 from Main Street to Wall Street to work together to create and expand employment opportunities for individuals with Down syndrome. NDSS is proud to be working with many like-minded businesses, among them: Voya Financial, Blake's Snow Shack, Alix Partners, Starbucks, DC Capitol Candy Jar, Little Caesar's and the Four Seasons Hotel.

#DSWORKS® Program Success Story



HARRISON VANDERLEE

Inspired by the success of their UK partners, Alix Partners, a management services company based in New York City, decided to expand their work force to include Harrison Vanderlee in the summer of 2017. An intern for Corporate Services, Harrison worked two days a week in the New York City office. As part of the Even Strength program via NDSS, Harrison and his colleagues at Alix Partners successfully worked together, focusing on a mentor program for Harrison, providing the support and confidence to make for a successful summer internship.

Due to the success of the program, Harrison returned to Alix Partners the summer of 2018, after completing his sophomore year at the College of Charleston, as part of the REACH program.

In a recent employment panel featuring #DSWORKS® Program Manager, Alix Partners mentor and colleague, Cameron Gibbs, Vice President Financial Advisory Services, and Harrison Vanderlee, Harrison spoke about what made his time at Alix Partners a success. "Having a friend like Cameron take time to make me feel like I am on a team is why I am always happy to work at Alix Partners." It was evident that Harrison's success stemmed from the ongoing support from his colleagues, most notably from Cameron who stated at the panel, "Alix Partners introducing this program and introducing me to Harrison made me a better employee, friend, and mentor. Having a mentor will always make this program a success and I was lucky to be Harrison's."

Due to the success of the internship program in New York City, our partners at Alix Partners expanded the program to their Southfield, MI office in the summer of 2018, adding another intern with Down syndrome to their staff.

JAMIE ROLAND

"Voya's support of the special needs community is part of our diversity and inclusion strategy and who the company is — and employees view these efforts with pride. We believe a diverse workforce in which all viewpoints are heard and respected, ultimately makes a more effective organization, allowing us to better serve our customers. Voya has long partnered with the National Down Syndrome Society from a CR and Foundation perspective, and we were thrilled to be able to expand our relationship by offering an opportunity to Jamie through the organization.

Jamie, who started his role at Voya on March 19, 2018, has come to Voya with a "can do" attitude. He is hard working and adds positivity to the different areas where he contributes. After Jamie had the opportunity to shadow our "Money In/Out" team that oversees much of our mail processing, we discovered how well these roles and responsibilities matched Jamie's past experience, and we truly had a need for help in the department. Jamie acclimated to both the new assignment and the team effortlessly and his contributions helped to accomplish the team's daily deliverables. It was a win/win for everyone!

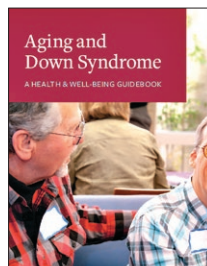
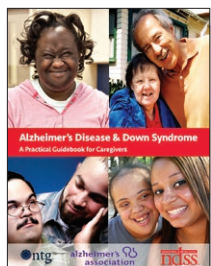
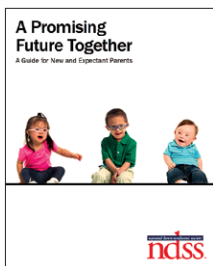
Jamie is partnered with a job coach through New England Business Associates (NEBA). NEBA has provided Voya with educational tools to leverage so we can support Jamie to be both independent and successful in his role." — **Lisa Fleury, Vice President, Talent Acquisition**

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

In November 2017, in honor of National Family Caregivers Month, NDSS released our most recent publication: "Alzheimer's Disease and Down Syndrome: A Practical Guide for Caregivers."

The risk of Alzheimer's disease in adults with Down syndrome can stir deep feelings of fear and anxiety for family, friends and caregivers who are otherwise trying to focus on supporting and celebrating a healthy and fulfilling adult life for an individual that they love. Education is one way to reclaim some power over a situation where it is impossible to have total control. 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.



Jadene Ransdel is one of the leading forces behind the NDSS Down Syndrome Adult Summit.

When Jadene, the proud mother of Matt, an individual who happens to have a dual diagnosis, realized that Matt began demonstrating signs of Alzheimer's disease she went into "Super Mom" mode.

Jadene began researching the connection between Down syndrome and Alzheimer's and dreamed of a conference for adults with Down syndrome, their families, friends and caregivers. NDSS, realizing the lack of information in the adult space, was thrilled to collaborate with Jadene to make this conference available for the entire Down syndrome community.

Thanks to Jadene, her dream is now a reality. The inaugural NDSS Down Syndrome Adult Summit was successfully hosted in April 2018. NDSS is thrilled to be taking the Adult Summit on the road in 2019 to Detroit to continue to share critical information about adults with Down syndrome.

NDSS Scholarship Programs

NDSS is proud to offer various scholarships and grants for self-advocates, including, the O'Neill Tabani Enrichment Fund, the #DSWORKS® Blake Pyron Entrepreneurship Scholarship and the Ethan Saylor Memorial 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 2018 NDSS Scholarship Recipients are:

Ethan Saylor Memorial Scholarship:

Alyssa Patrias

NDSS #DSWORKS® Blake Pyron Entrepreneurship Scholarship:

Joseph Steffy

*Samuel Myers

*Ana Morales

*Gabrielle Angelini

*Allison Fogarty

**were given honorary scholarships due to the support of an angel donor*

O'Neill Tabani Enrichment Fund:

Isabella Ketchum

Erin Scully

Jake Pratt

Mary Catherine Price

Zachary Smith

Olivia Parry

Jonathan Peay

Kathleen Spadaro

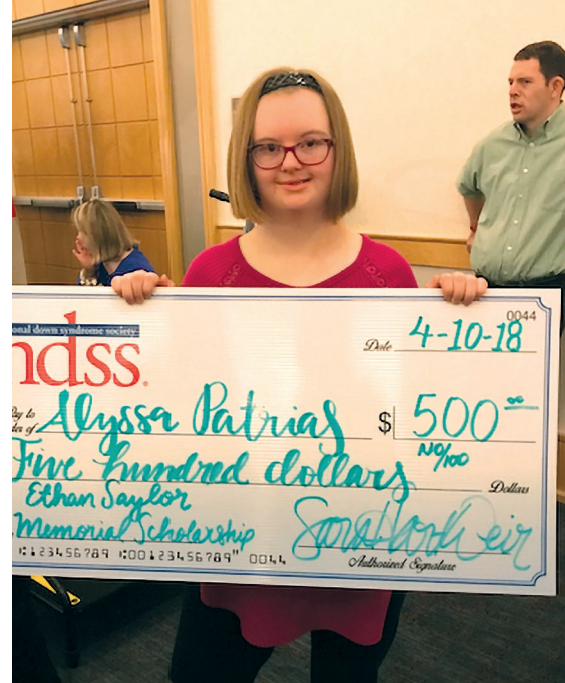
Sam Dess

Mary Borman

Matthew Strachan

Dan Piper Award:

Benjamin Pelham



#TeamNDSS / Athlete Ambassadors

Since launching the NDSS Athlete Ambassador Program in 2017, the team has grown to more than 100 dedicated Athletes. The 2017-2018 Athlete Ambassador team featured Kayleigh Williamson, a self-advocate from Austin, Texas who completed the Austin Half Marathon for her second year in a row! NDSS also supported Athlete Ambassador and Board Member, Mark Johnson, who completed a solo Double Ironman in March 2018 and raised more than \$28,000 in honor of his sister, Wendy, and all individuals with Down syndrome.

This program has allowed NDSS to secure incredible sports-focused retail partners, including Altra Running, Newton Running, RxBars, Zewnsahm, Flipbelt, Headsweats, Honey Stinger, GU, Bombas, Nuun, RunLites, Specialized, Running Warehouse and Road ID, who have helped make all #TeamNDSS events possible over the past year.

The Athlete Ambassador Program continues to grow, offering various opportunities to foster new partnerships and highlight the successes of athletes representing NDSS nationwide through various sports and activities!

Run for 3.21 on World Down Syndrome Day

Run for 3.21 is a three-day, 250+ mile adventure from Washington, D.C. to New York City. The run brought 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 amazing run culminated in a presentation at the U.N. on World Down Syndrome Day, March 21, where NDSS showcased its mission as the leading human rights organization for all individuals with Down syndrome; the team raised more than \$98,000 to support NDSS' mission. The Down syndrome community rallied to support these runners within local route communities and virtually by watching the live-streamed finish line video.

Racing for 3.21 on World Down Syndrome Day

On March 21, 2018, NDSS welcomed more than 2,000 people to the "virtual" Racing for 3.21 event. This annual 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. The event resulted in more than \$102,000 raised and brought together schools, communities and businesses to promote health and fitness in the Down syndrome community.

Charity Racing Teams

In 2017 and 2018, NDSS brought Charity Racing teams to various events, including the Army 10-Miler, the Marine Corps Marathon, the New York City Marathon and the Walt Disney World Marathon Weekend presented by Cigna. More than 100 runners participated on behalf of NDSS, raising more than \$100,000 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 and the Disney Princess Half Marathon Weekend presented by Children's Miracle Network Hospitals®.



"My son is my inspiration to run, he gives purpose to my miles like no one else can. It feels amazing to know that I am helping to spread awareness and advocate for not only my son, but for all individuals with Down syndrome. My journey with #TeamNDSS has only just begun and I have already seen the impact this is making on myself, my family and those around us."

- Courtney Frost

NDSS Outreach & Special Events

C21

C21 is a pop-up restaurant offering a one-of-a-kind dining experience. Its name refers to the tripled 21st chromosome that is characteristic of Down syndrome. This event showcases to the world that individuals with Down syndrome are ready, willing and able to work. C21 popped up on Capitol Hill in Eastern Market on Oct. 2, 2017 and was exclusively run by nearly 40 individuals with Down syndrome – its doors welcomed several Members of Congress, parents of self-advocates and other VIP guests.

The magical night ended with a call-to-action for guests to take action against the laws that prevent individuals with Down syndrome from seeking full-time employment, such as working in a restaurant. Thus, the #LawSyndrome campaign was launched. #LawSyndrome aims to raise awareness of antiquated laws that hinder individuals with Down syndrome from pursuing a career, getting married or living independently. #LawSyndrome focuses not on ability, but on the legal restrictions holding back the community.

C21 has gained such success that the restaurant is now popping up in locations across the country and has already been hosted in New York City with future events scheduled in Atlanta and Dallas.

NDSS Inaugural DC Golf Outing

NDSS welcomed more than 60 guests to share the day at the Belle Have Country Club in Alexandria, VA for the inaugural D.C. Golf Outing on Oct. 23, 2017. The hosts of the event were: U.S. Sen. Richard Burr, U.S. Reps. Cathy McMorris Rodgers, Bill Huizenga, Pete Sessions, Cheri Bustos and Assistant Democratic Leader Jim Clyburn, all of whom made this event possible.

For nearly four decades, NDSS has been an organization that has provided comprehensive programming to all individuals with Down syndrome and their families. This event raised \$67,740, and enables NDSS to provide state-of-the-art, comprehensive programs to the Down syndrome community.

NDSS 32nd Annual Gala & Auction

The 32nd Annual Gala and Auction was hosted at Gotham Hall in New York City on March 8, 2018.

This year's gala, with the inspirational theme, "To Grow, To Build, To Inspire," gathered together more than 300 friends and supporters and raised \$356,565 to celebrate the NDSS mission, the accomplishments of individuals with Down syndrome and those who contribute to the Down syndrome community.



NDSS recognized three incredible honorees for their contributions to the Down syndrome community:

Dave Burton, owner of The Capital Candy Jar, whose employees include several adults with Down syndrome.

John Cronin, co-founder of John's Crazy Socks. A year into their mission of spreading happiness, John and his father have generated more than \$1.4 million in revenue, have raised \$30,000 for charity and have shipped their Crazy Socks internationally.

Saatchi and Saatchi was NDSS' surprise tribute, who NDSS was honored to recognize for their generously donated time, talent and treasure to the End #LawSyndrome campaign.

These innovators, entrepreneurs and organizations work with NDSS to carry an important and inspiring transformational message throughout the world and help us achieve our NDSS vision — *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.*

21st Annual NDSS Golf Outing

This year was the 21st year bringing together a group of dedicated golfers to help raise funds for NDSS. The 21st Annual NDSS Golf Outing on June 8, 2017 celebrated the importance of inclusion and the value of individuals with Down syndrome. Golfers took the course for the first time at The Stanwich Club in Greenwich, Conn.

NDSS Even Strength Golf Tournament

On July 18, 2017, a group of enthusiastic golfers, NDSS staff members and NHL players gathered in New England at the Renaissance in Haverhill, Mass. for first-ever Even Strength Golf Tournament and raised \$34,264 in support of our Even Strength Internship Program. Coupled with the NDSS #DSWORKS® Program, NDSS partnered with professional sports organizations to bring exciting and high profile internships to career-coached young adults with Down syndrome. As an internship and employment program, Even Strength provides individuals with Down syndrome the opportunity to work on the game day operations staff of professional sports teams where they learn and acquire job-related skills to use in future employment. The goal is to encourage corporations and businesses to invest in hiring people with Down syndrome and to increase the number of opportunities for individuals with Down syndrome to work in meaningful and competitive employment settings.

NDSS' CARING WITH CONGRESS

On July 12, 2017, NDSS hosted its annual "Caring with Congress" event in Washington, DC, with the bipartisan members of the Congressional Task Force on Down Syndrome. The event raises funds for the NDSS Research Innovation and Discovery Fund, which supports advocacy on behalf of the Down syndrome scientific and research community.

Proceeds from the 2017 "Caring with Congress" event were used to host a strategic planning meeting of the NDSS Science and Clinical Advisory Board in Washington, DC on March 7-8, 2018. The meeting included a reception with the Congressional Task Force on Down Syndrome, as well as meetings with Members of Congress and their staff to discuss how advances in clinical and biomedical research are improving the lives of individuals with Down syndrome. In addition, proceeds were used to partner with the Down Syndrome Association of Central Ohio to organize a research awareness event on August 26, 2017 to educate families on the importance of clinical studies, increase participation in DS Connect (the Down syndrome patient registry), and enroll individuals in local and national research studies.

NDSS wishes to recognize and thank the 2017 event's corporate sponsors, which included the Pharmaceutical Research and Manufacturers of America, the Independent Insurance Agents and Brokers of America, Rite Aid, Fluor Corporation, Federated Investors, the National Association of Realtors, Koch Industries, the Advanced Medical Technology Association, the American Financial Services Association, the Council of Insurance Agents and Brokers, Darren Willcox, the Altria Group, K&L Gates, Maggiano's Little Italy and Prudential Financial.

Statements of Financial Position

March 31, 2018 (with comparative Information for 2017)

Assets

	2018	2017
Cash and cash equivalents	\$ 754,279	\$ 479,112
Contributions receivable	\$ 158,226	\$ 1,831,612
Investments, at fair value	\$ 11,140,611	\$ 9,813,396
Prepaid expenses and other assets	\$ 136,614	\$ 115,091
Property and equipment, net	\$ 67,865	\$ 24,752
Total Assets	\$12,257,595	\$12,263,963

Liabilities and Net Assets

LIABILITIES

Accounts payable and accrued expenses	\$ 253,164	\$ 263,800
Deferred rent	\$ 109,875	\$ 86,193
Deferred revenue	\$ 9,936	\$ 52,980
Total Liabilities	\$ 372,975	\$ 402,973

NET ASSETS

Unrestricted:		
Undesignated	\$ 3,612,902	\$ 4,116,024
Board designated:		
Endowment	\$ 6,792,652	\$ 6,200,000
Temporarily restricted	\$ 405,625	\$ 471,525
Permanently restricted	\$ 1,073,441	\$ 1,073,441
Total Liabilities	\$ 11,884,620	\$ 11,860,990
Total Liabilities & Net Assets	\$ 12,257,595	\$ 12,263,963

Statements of Activities

March 31, 2018 (with comparative information for 2017)

				Total	
	UNRESTRICTED	TEMPORARILY RESTRICTED	PERMANENTLY RESTRICTED	2018	2017
Revenue & Other Support					
Contributions	\$ 1,778,444	\$ 187,991	-	\$ 1,966,435	\$ 2,559,795
National Buddy Walk	-	\$ 419,790	-	\$ 419,790	\$ 481,173
In-kind Contributions	\$ 792,637	-	-	\$ 792,637	\$ 121,860
Special Events	\$ 808,011	-	-	-	-
Less: Direct Benefit Costs	(420,395)	\$ 387,616	-	\$ 387,616	\$ 377,851
Gain on Sale of Office Condominium	-	-	-	-	\$ 5,926,413
Rental Income, net	-	-	-	-	\$ 22,740
Conference Income	\$ 35,911	-	-	\$ 35,911	\$ 17,221
Miscellaneous Income	\$ 32,013	-	-	\$ 32,013	\$ 6,003
Net Assets Released from Restrictions	\$ 673,681	(673,681)	-	-	-
Total Revenue and Other Support	\$ 3,700,302	(65,900)	-	\$ 3,634,402	\$ 9,513,056
Expenses					
Program Services					
Public Policy	\$ 401,621	-	-	\$ 401,621	\$ 410,260
Public Awareness	\$ 1,960,055	-	-	\$ 1,960,055	\$ 332,515
Buddy Walks	\$ 284,759	-	-	\$ 284,759	\$ 301,395
Community Relations	\$ 853,028	-	-	\$ 853,028	\$ 515,281
Total Program Services	\$ 3,499,463	-	-	\$ 3,499,463	\$ 1,559,451
Support services					
Management and General	\$ 326,168	-	-	\$ 326,168	\$ 329,392
Fund Raising	\$ 681,030	-	-	\$ 681,030	\$ 229,600
Total Supporting Services	\$ 1,007,198	-	-	\$ 1,007,198	\$ 558,992
Total expenses	\$ 4,506,661	-	-	\$ 4,506,661	\$ 2,118,443
Change in Net Assets Before Investment Income	\$ (806,359)	\$ (65,900)	-	\$ (872,259)	\$ 7,394,613
Investment Income (loss)	\$ 895,889	-	-	\$ 895,889	\$ 810,533
Change in Net Assets	\$ 89,530	\$ (65,900)	-	\$ 23,630	\$ 8,205,146
Net Assets, Beginning of Year	\$ 10,316,024	\$ 471,525	\$ 1,073,441	\$ 11,860,990	\$ 3,655,844
Net Assets, End of Year	\$ 10,405,554	\$ 405,625	\$ 1,073,441	\$ 11,884,620	\$ 11,860,990

NDSS Staff

Sara Hart Weir, MS

President and CEO

Keisha Landry

Chief of Staff

Elizabeth Etter

Executive Assistant to the President

Kandi Pickard

Senior Vice President of Philanthropy, Outreach and Events

Joshua Harlow

Director of Communications

Ashley Helsing

Director of Government Relations

Sara Jo Soldovieri

Manager of Inclusive Education Programming

Colleen Hatcher

Community Outreach and Engagement Manager

Caleb Herr

Outreach and Operations Manager

Melissa Robertson

Manager of Operations

Kayla McKeon

Manager of Grassroots Advocacy

Nicole Patton

Manager of Grassroots Advocacy

Michelle Sagan

National Buddy Walk® Program Manager

Emily Kaczmarczyk

#DSWORKS® Program Manager

Rachel Grimm

Special Events and Conference Coordinator

Charlotte Woodward

Community Outreach Associate

Jamie Dolan

Information and Referral Assistant

Luke Hickey

Special Events Assistant

Adrian Forsythe

Advocacy Programs Specialist

Michelle Ray

Senior Advisor, National Inclusive Health & Sports Program

Vince Randazzo

Public Policy Advisor



Elizabeth F. Goodwin
Founder

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Charles H. Gerhardt, III, JD

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Annette Halprin

Mark Johnson

Rick Kosmalski

Heather Lavallee

Honorable Jim Nussle

Roger Reeves, PhD

Brian Rodgers

Erin Thompson

Laurie Walters

Tim Wilbricht

Office locations

**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

About Down Syndrome

Down syndrome is a genetic condition that occurs in approximately one in every 700 babies born in the United States. It is the most frequently occurring chromosomal condition and is found in people of all races and economic levels. More than 400,000 people in the United States have Down syndrome.

A few of the common physical traits associated with Down syndrome are low muscle tone, small stature, an upward slant to the eyes and a single deep crease across the center of the palm. Every person with Down syndrome is a unique individual and may possess these characteristics to differing degrees or not at all.

People with Down syndrome have an increased risk for certain medical conditions such as congenital heart defects, respiratory and hearing problems and Alzheimer's disease, childhood leukemia and thyroid conditions. However, many of these conditions are now treatable, so most people with Down syndrome lead healthy lives. Life expectancy for people with Down syndrome has increased dramatically in recent decades – from 25 in 1983 to 60 today.

People with Down syndrome experience cognitive delays, but the effect is usually mild to moderate and is not indicative of the many strengths and talents that each individual possesses. Children with Down syndrome learn to sit, walk, talk, play and do most other activities; only somewhat later than their peers without Down syndrome.

Quality educational programs, a stimulating home environment, good health care and positive support from family, friends and the community enable people with Down syndrome to develop their full potential and lead fulfilling lives. People with Down syndrome attend school, work and contribute to society in many wonderful ways.

Researchers are making great strides in identifying the genes on chromosome 21 which cause the characteristics of Down syndrome. Many feel strongly that it will be possible to improve, correct or prevent many of the problems associated with Down syndrome in the future.





2018 Annual Report

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