# 2014 Annual Report
(April 1, 2014-March 31, 2015)

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NDSS Advocates & Friends:

On behalf of our organization, the National Down Syndrome Society (NDSS), we are grateful for the generous support and dedication to our mission from advocates across the country. NDSS remains the largest nonprofit organization representing the more than 400,000 Americans with Down syndrome in the US with a vital mission – to be national advocate for the value, acceptance and inclusion of people with Down syndrome. This was an incredible year for NDSS, and we continued to provide state-of-the-art, comprehensive programs to the Down syndrome community, specifically:

- Our NDSS Advocacy & Policy Center creates systemic change through federal and state legislative advocacy – priorities include increasing education opportunities, creating an economic future for individuals with Down syndrome, improving health outcomes and increasing opportunities for adults with Down syndrome,
- The National Buddy Walk® Program honors and celebrates individuals in their communities
- Public awareness initiatives bring positive presentations of Down syndrome to the public – combating stereotypes and igniting a new way for the public to think about people with Down syndrome,
- And, community support programs provide comprehensive and accurate information and resources on Down syndrome.

We have a very long, rich history of advocating for and supporting people with Down syndrome and their families. Betsy Goodwin founded our organization around her kitchen table in 1979, after her daughter, Carson, was born. On December 19, 2014, we also celebrated the landmark passage of the Stephen Beck Jr., Achieving a Better Life Experience (ABLE) Act (PL 113-295), an advocacy effort spearheaded by NDSS for almost a decade, and like NDSS, was another bright idea and monumental achievement for people with Down syndrome formed around a kitchen table by dedicated parents and advocates. The ABLE Act earned the support of over 85% of the 113th US Congress – with 381 US Representatives and 74 US Senators, and allows individuals with Down syndrome to establish ABLE Accounts to save money tax-free. We couldn’t be more proud that the ABLE Act is now the law of the land!

Our NDSS National Buddy Walk® Program had a record-breaking year with more than 315,000 participants raising more than $13 million for the Down syndrome community. Our Buddy Walk® Program was ranked among the top 30 fundraising events nationwide, ranked No. 29 for money raised, No. 13 for number of events and No. 7 for overall number of participants.

Our NDSS DS-AMBASSADOR™ program grew to over 250 NDSS DS-Ambassadors™ this year, with the goal of building relationships with Members of Congress to raise awareness and advocate for policy solutions that benefit the Down syndrome community. NDSS continued to set the standard in distributing accurate, up-to-date information on Down syndrome for the community. More than 8,000 copies of our New and Expectant Parent Guide and our Aging and Down syndrome: A Health and Well-being Guidebook were distributed.

At NDSS, we envision a world in which all people with Down syndrome have the opportunity enhance their quality of life, realize their life aspirations, and become valued members of welcoming community. We are thrilled that you have chosen to be a part of our NDSS vision for the future of all people with Down syndrome in the US. On behalf of NDSS, we are beyond grateful all you do for NDSS and people with Down syndrome.

With our deepest gratitude,

Sara Hart Weir, MS
President

Capt. Robert P. Taishoff USN (ret.)
Chairman
The mission of the National Down Syndrome Society (NDSS) is to be the national advocate for the value, acceptance and inclusion of people with Down syndrome.

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

Down syndrome is a genetic condition that occurs in one in every 691 births. 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 of 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 different 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, 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 to 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 and work and contribute to society in many wonderful ways.
Researchers are making great strides in identifying the genes on chromosome 21 that 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.
About NDSS

NDSS has worked since 1979 to benefit people with Down syndrome and their families through national leadership in education, research and advocacy. NDSS was founded by Elizabeth 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. Elizabeth subsequently established NDSS in order to address the pressing needs of people with Down syndrome and their families.

NDSS Programmatic Updates

NDSS has four cutting-edge, state-of-the-art programmatic pillars that support our platform as the largest nonprofit organization in the US representing people with Down syndrome and their families. These programmatic pillars include the following:

- National Advocacy & Policy Center
- National Buddy Walk® Program
- Public Awareness & Communications
- Down Syndrome Community Outreach & Support
NDSS National Advocacy & Policy Center

Our NDSS National Advocacy & Policy Center strives to protect the rights and remove barriers for all individuals with Down syndrome. Our National Advocacy & Policy Center, located in Washington, DC, facilitates and mobilizes advocacy efforts for federal, state and local policies that positively impact people with Down syndrome across the country.

The work of the National Advocacy & Policy Center is guided by its dynamic legislative agenda, which includes a wide range of issues and touches every stage of life, these include:

- Improving Health Outcomes & Quality of Life for People with Down Syndrome
- Improving Education Opportunities for People with Down Syndrome
- Increasing Opportunities for Adults with Down Syndrome
- Creating an Economic Future for Individuals with Down Syndrome

Our advocacy programs are designed to support all advocates by recognizing there are varying levels of volunteer involvement, and focus on federal, state and local advocacy. NDSS works with Congress and Federal Agencies to develop and improve legislation, organize and participate in coalitions of national disability organizations and lead national and statewide Governmental Affairs Committees. NDSS also leads a state-of-the-art national advocacy program, the NDSS DS-AMBASSADOR™ program.
NDSS 2014-2015 Accomplishments:

- **NDSS hosted the annual 2015 Buddy Walk® on Washington**, our advocacy conference in Washington, DC, with more than 190 participants from 24 states on Capitol Hill and held meetings with more than 200 Congressional offices.

- **NDSS spearheaded the advocacy effort behind the passage of the *Stephen Beck Jr., Achieving a Better Life Experience (ABLE) Act*** - a landmark law supported by more than 85% of the 113th US Congress that was signed into law by President Barack Obama on December 19th, 2014.

- **NDSS led a national initiative called the NDSS DS-AMBASSADOR™ program** to support the organization’s federal legislative efforts to advocate for the value, acceptance and inclusion of people with Down syndrome in all 50 states, and to date, we have more than 250 DS-Ambassadors™ in all 50 states.
NDSS National Buddy Walk® Program

Since 1995, the Buddy Walk® continues to be the premier awareness and advocacy 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.

NDSS 2014-2015 Accomplishments:

- Over $13 million was raised in more than 250 Buddy Walks® across the country and around the world to support local programs and services and NDSS’ advocacy initiatives

- More than 315,000 participants were involved with the Buddy Walk® in 2014

- Since 2008, the National Buddy Walk® program has been ranked in the top 30 fundraising events nationwide by the Peer-to-Peer Professional Forum and the Buddy Walk® ranked No. 29 for money raised, No. 13 for number of events and No. 7 for number of participants

- The Buddy Walk® program expanded internationally with events in Japan, New Zealand, Trinidad and Tobago, Bermuda and Canada

Z. Goff Photography
**NDSS Public Awareness & Initiatives**

The purpose of public awareness at NDSS is to turn the mission of “value, acceptance and inclusion” into a comprehensive national public awareness message. NDSS proactively reaches out to national media outlets, including television, print, radio, online and social media to secure editorial content on issues within the Down syndrome community as well as disseminate positive and inspirational news stories.

NDSS monitors all forms of media on a daily basis, 365 days a year, and responds to any inappropriate comments in an ongoing effort to educate and promote accurate and positive messaging about Down syndrome.

The NDSS My Great Story public awareness campaign seeks to ignite a new way of thinking about people with Down syndrome by sharing and telling stories, which are displayed in a beautiful online storybook on the NDSS website. The stories are written by people with Down syndrome, their family members, friends, coworkers, teachers and others. Public service announcements for the campaign in both print and digital forms have been featured in national and local media outlets across the country.

**NDSS 2014-2015 Accomplishments:**

- **Our NDSS website** is a comprehensive and up-to-date resource for self-advocates, families, professionals, affiliates and other key stakeholders

- NDSS.org receives more than three million page views each year and includes an extensive Spanish translation

- This year, the NDSS website received more than 1.3 million visits, a 120% increase over the prior year

- **Our NDSS Social Media** platform continued to lead the way in the Down syndrome community, and by the end of the fiscal year, NDSS’ Facebook page grew by 45% to more than 91,000 likes, our NDSS Twitter had more than a 43% increase from the previous year with more than 8,700 followers

- **NDSS was featured** in multiple forms of news coverage around the country on a variety of topics related to Down syndrome in the New York Times, Wall Street Journal, USA Today, NPR, Al-Jazeera America and many other national outlets
NDSS Down Syndrome Community Outreach & Support

NDSS maintains a network of more than 375 local Down syndrome affiliates, and our organization provides an array of programs, services and resources to the Down syndrome community.

Some key resources NDSS offers the Down syndrome community and its affiliates:

The Goodwin Family Information & Referral Center

Through our toll-free helpline and email service, NDSS receives more than 8,000 requests a year for information on Down syndrome. The Goodwin Family Information and Referral Center is also supported by a translation service that can be accessed in over 150 languages.

Publications

NDSS publishes new and expectant parent guides and informational brochures in both English and Spanish. This past year, NDSS also published a guidebook titled Aging and Down syndrome: A Health and Well-being Guidebook targeted toward parents and caregivers of adults with Down syndrome.

Webinars

NDSS hosted a very successful monthly webinar series with an average audience of 400 participants per month. Our educational webinars cover topics related to health, education, advocacy, family life, research and more.
Scholarships

Our NDSS O’Neill-Tabani Enrichment Fund was established in 2005 by Joshua O’Neill and along with his family and their friend, Zeshan Tabani. Joshua is an inspirational young man, who happens to have Down syndrome. Joshua and Zeshan grew up in the same neighborhood in Indiana.

Our scholarships are given annually to those applying for postsecondary education and/or considering taking courses. This year, the award was given to fourteen recipients from across the country.
Board of Directors & Staff

NDSS is guided by a Board of Directors who represent a broad range of expertise and experience. Our advisory boards comprise internationally recognized professionals who are leaders in their field.

NDSS Board Of Directors

Elizabeth F Goodwin  Founder
Amy G. Allyn
Peter Amadeo
Paul Brunswick

CAPT Robert P. Taishoff USN (ret)  Chairman
Julie Cevallos
Janet Slaughter Eissenstat
Charles H. Gerhardt, III, JD

Stephen Beck Jr.  Vice Chairman
Rick Kosmalski
Honorable Jim Nussle
Roger Reeves, PhD

Tiffany Barfield  Secretary
Charles Symington
Kimberly Templeton, JD
Erin Thompson

F. Gordon Spoor, CPA, PFS, CGMA  Treasurer
Laurie Walters
Tim Wilbricht
Sara C. Wolff

NDSS Self-Advocate Advisory Board

Sara Wolff, Secretary  Essie Pederson
Chris Burke  Mia Peterson
Tavrick Lawless  Anita Raghavan
Mitchell Levitz  Erin Thompson

Scientific & Clinical Advisory Board

Stephanie L. Sherman, PhD, Chairperson  William C. Mobley, MD, PhD
Paul Moore, MD
George T. Capone  William Motley, MD, MS
Jessica DeBord, DDS  Lynn Nadel, PhD
Terry Hassold, PhD  Bonnie Patterson, MD
Priya Kishnani, MD  David Patterson, PhD
Julie R. Korenberg, PhD, MD  Roger H. Reeves, PhD
Len Leshin, MD  Nancy J. Roizen, MD
Ira T. Lott, MD  Romney L. Synder-Croft, LCSW, ACSW
Phillip Mattheis, MD  Leslie Walker-Hirsch, Med, FAAIDD
Joan Guthrie Medlen, RD  Patricia C. Winders, PT
National Government Affairs Committee

Ann Cammack
Teddy Eynon, JD
Charles H. Gerhardt, III, JD, Chair
Honorable Jim Nussle
Charles Symington
Kimberly Templeton
Kandi Terry

Honorary Board of Governors

Thomas J. O’Neill, Chairperson
Emily Pearl Kingsley
Arden G. Moulton

NDSS Staff List (in alphabetical order)

Madeline Alemar
*Director, Special Events & NDSS Your Way*

Mark Priceman
*Vice President, Communications & Marketing*

Kjerstin Besser
*Information & Referral Specialist*

Vanessa Quick
*Director, Educational Programming*

Chris Burke
*Goodwill Ambassador*

Heather Sachs
*Director, State Government Affairs*

Anita Ford
*Buddy Walk® Associate*

Ginny Sessions
*Manager, Grassroots & Advocacy*

Kristie Hagen
*Manager, Communications & Social Media*

Rebecca Switalski
*Director, National Buddy Walk®*

Harry Jellinek
*Director, Finance*

Sara Hart Weir, MS
*President*
## Statements of Financial Position

March 31, 2015 and 2014  
(With Summarized Comparative Information for 2014)

### Assets

<table>
<thead>
<tr>
<th></th>
<th>2015</th>
<th>2014</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cash and cash equivalents</td>
<td>$275,644</td>
<td>$228,437</td>
</tr>
<tr>
<td>Contributions receivable, net</td>
<td>79,350</td>
<td>54,880</td>
</tr>
<tr>
<td>Investments, at fair value</td>
<td>3,346,652</td>
<td>3,520,701</td>
</tr>
<tr>
<td>Accrued interest receivable</td>
<td>2,513</td>
<td>2,313</td>
</tr>
<tr>
<td>Prepaid expenses and other assets</td>
<td>67,760</td>
<td>48,870</td>
</tr>
<tr>
<td>Property and equipment, net</td>
<td>279,975</td>
<td>336,443</td>
</tr>
<tr>
<td><strong>Total assets</strong></td>
<td><strong>$4,051,894</strong></td>
<td><strong>$4,191,644</strong></td>
</tr>
</tbody>
</table>

### Liabilities and Net Assets

#### Liabilities

<table>
<thead>
<tr>
<th></th>
<th>2015</th>
<th>2014</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accounts payable and accrued expenses</td>
<td>$157,686</td>
<td>$170,134</td>
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<tr>
<td>Other liabilities</td>
<td>19,964</td>
<td>27,908</td>
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<tr>
<td><strong>Total liabilities</strong></td>
<td><strong>177,650</strong></td>
<td><strong>198,042</strong></td>
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</table>

#### Net Assets

<table>
<thead>
<tr>
<th></th>
<th>2015</th>
<th>2014</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unrestricted</td>
<td>2,298,828</td>
<td>2,532,714</td>
</tr>
<tr>
<td>Temporarily restricted</td>
<td>501,975</td>
<td>387,447</td>
</tr>
<tr>
<td>Permanently restricted</td>
<td>1,073,441</td>
<td>1,073,441</td>
</tr>
<tr>
<td><strong>Total net assets</strong></td>
<td><strong>3,874,244</strong></td>
<td><strong>3,993,602</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>2015</th>
<th>2014</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total liabilities and net assets</strong></td>
<td><strong>$4,051,894</strong></td>
<td><strong>$4,191,644</strong></td>
</tr>
</tbody>
</table>

The accompanying notes are an integral part of these financial statements.
## National Down Syndrome Society
### Statements of Activities
#### Years Ended March 31, 2015 and 2014
(With Summarized Comparative Information for 2014)

<table>
<thead>
<tr>
<th>Unrestricted</th>
<th>Temporarily Restricted</th>
<th>Permanently Restricted</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Revenue and Other Support</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Contributions</td>
<td>$ 890,979</td>
<td>$ 86,188</td>
<td>-</td>
</tr>
<tr>
<td>National Buddy Walk</td>
<td>-</td>
<td>475,979</td>
<td>-</td>
</tr>
<tr>
<td>In-kind contributions</td>
<td>104,649</td>
<td>13,186</td>
<td>-</td>
</tr>
<tr>
<td>Special events</td>
<td>$ 871,248</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Less: direct benefit costs</td>
<td>(469,931)</td>
<td>249,976</td>
<td>151,341</td>
</tr>
<tr>
<td>Rental income</td>
<td>85,049</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Less: related occupancy expenses</td>
<td>(22,634)</td>
<td>62,415</td>
<td>-</td>
</tr>
<tr>
<td>Booklets, films and educational materials</td>
<td>9,686</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Conference income</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Miscellaneous income</td>
<td>9,906</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Net assets released from restrictions</td>
<td>691,616</td>
<td>(691,616)</td>
<td>-</td>
</tr>
<tr>
<td>Total revenues and other support</td>
<td>2,019,227</td>
<td>35,078</td>
<td>-</td>
</tr>
<tr>
<td><strong>Expenses</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Program services</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Public policy</td>
<td>447,513</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Public awareness</td>
<td>409,406</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Buddy Walks</td>
<td>426,143</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Community relations</td>
<td>516,217</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Total program services</td>
<td>1,799,279</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Support services</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Management and general</td>
<td>224,234</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Fund raising</td>
<td>346,519</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Total supporting services</td>
<td>570,753</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Total expenses</td>
<td>2,370,032</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Change in net assets before investment income</td>
<td>(350,805)</td>
<td>35,078</td>
<td>-</td>
</tr>
<tr>
<td>Investment income</td>
<td>116,919</td>
<td>79,450</td>
<td>-</td>
</tr>
<tr>
<td>Change in net assets</td>
<td>(233,886)</td>
<td>114,528</td>
<td>-</td>
</tr>
<tr>
<td>Net assets, beginning of year</td>
<td>2,532,714</td>
<td>387,447</td>
<td>1,073,441</td>
</tr>
<tr>
<td>Net assets, end of year</td>
<td>$ 2,298,828</td>
<td>$ 501,975</td>
<td>$ 1,073,441</td>
</tr>
</tbody>
</table>

The accompanying notes are an integral part of these financial statements.