Executive Leadership’s Message

Dear Friends,

“FAMILY IS EVERYTHING” was the HDSA battle cry in 2014. We had an amazing year reaching more people with our mission work than ever before. With our comprehensive advocacy, education and research programs, HDSA is bringing the awareness, understanding and answers that improve the lives of everyone affected by Huntington’s disease.

Our two hallmark programs — the HDSA Centers of Excellence and HD Human Biology Projects — saw exponential growth in 2014. The launch of the new Center of Excellence grant program mid-2014 resulted in 29 outstanding multi-disciplinary care centers around the United States — a 45 percent increase from the prior year’s 20 Centers — receiving the prestigious designation by HDSA. Additionally, nine Human Biology Projects received HDSA awards to study innovative clinical HD science. This represents a more than doubling of the program in only its second year and illustrates the importance and impact of this program.

At the 29th Annual HDSA Convention in Louisville, Kentucky, HDSA launched its new Huntington’s disease news app that is available for all mobile devices. Titled “HD News” and available through iTunes and Google Play, the free app provides up-to-date news and event information from HDSA.org, research summaries from HDBuzz.net, as well as the latest news related to HD drug discovery and development from Science Daily and Medical News Today. HD News is one-stop shopping for everyone who follows Huntington’s disease science and related news, and we’re excited to be able to provide the first customized news app for the HD community as we continue to look for new ways of bringing valuable information and support for families affected by Huntington’s disease.

Over the summer, the HD community came together to build awareness for Huntington’s disease with the campaign, HDSA’s Pie-in-the-Face Challenge. HD families, friends and supporters captured videos of themselves taking a pie in the face, as well as making generous financial contributions to HDSA. Online donations to HDSA for the month of the campaign more than tripled, and it was great to see the community work together in a fun and effective initiative to build awareness and funds for HD support and research.

From coast to coast, HDSA events generated an enormous amount of awareness and funds to support our mission work. Out west, the “Freeze HD” event in Los Angeles raised more than $100,000, and in the east the Methot family rode their bicycles 600 miles in New York to raise more than $20,000. These events and the hundreds of family-led events around the country are the lifeblood of the Huntington’s Disease Society of America and truly make our work possible.

At HDSA we never lose sight of our vision — a world free of Huntington’s disease. This dream is a guiding force behind everything we do to support families today and ensure that treatments and cures are available tomorrow, and it’s all made possible by your support of our mission.

Thank you for everything you do to get us closer to our vision. The HD community is stronger than ever before and we are looking forward to keeping this momentum moving forward into 2015.

Sincerely,

Jang-Ho Cha, M.D., Ph.D.
Chair, Board of Trustees

Louise Vetter
Chief Executive Officer
2014 Year In Review

29TH ANNUAL CONVENTION IN LOUISVILLE

The Huntington’s Disease Society of America hosted the 29th Annual Convention at the Galt House in Louisville, KY on July 20th–22nd. The Convention was the second largest in the event’s history with more than 850 guests in attendance. The Convention provided the world’s largest singular opportunity to personally learn from and build relationships with a wide cross-section of the HD community. The spectacular event offered insightful research seminars from top clinicians and scientists from around the world who provided optimistic research advancements. Festivities began on Thursday afternoon with the Team Hope kickoff walk around the Galt House with hundreds in attendance setting the tone for an incredible Convention. Among the many remarkable supporters recognized at Convention, Destiny Hand of Seaford, Delaware was honored with the HDSA Youth Leadership Award for her extraordinary efforts to raise awareness for HD. Hand, a high-school senior, is the volunteer coordinator of the Laurel, Delaware Team Hope Walk that raised over $10,000 on May 17th at Trap Pond State Park. She also serves as a representative advocating for children of HD families in both the National Youth Association and HDYO. Lauren Holder from North Carolina won the prestigious HDSA Person of the Year Award.

HD RESEARCH

In 2014, we saw the commencement of several exciting new trials for HD from major pharmaceutical companies and the completion of the First-HD and ARC-HD trials. However, we also heard of the unfortunate termination of the two largest trials ever conducted for HD, 2CARE and CREST-E. Without a doubt, the most exciting news of the year came when it was announced that in 2015 the first clinical trial for a huntingtin lowering drug will begin. While this is just the beginning for this drug, it marks a moment long in the making by scientists and even longer in waiting by HD patients and families. For the first time ever, a drug, specifically designed for Huntington’s disease, will finally get its chance in the clinic.

This year, HDSA significantly expanded our flagship research initiative, the HD Human Biology Project. In the 2014 Research Investor’s Report you will see summaries of the eight new research projects HDSA has begun to support. In addition, exciting data are now...
beginning to emerge from the labs of the 2013 Human Biology Project winners. The Human Biology Project was launched in 2013 as a critical piece of HDSA’s mission to support impactful HD research that will help guide us closer to effective therapies.

The research we support is all patient-centric and done in collaboration with HDSA Centers of Excellence with the goal of studying HD in humans. We believe this approach is critical for the acceleration of treatments for HD as everyone agrees that the most important observations to guide researchers in the hunt for therapies for HD will be those made in people actually affected by HD.

In February of 2014, the HDSA Board of Trustees made a strong statement to the community by formally endorsing the Enroll-HD study that is organized by the CHDI Foundation. Never before has HDSA endorsed a clinical study, but the organization felt strongly that the scope and potential impact of Enroll-HD required its full support. Enroll-HD, is a global, multi-faceted research platform that will help guide drug development, clinical trials and HD patient care for years to come. HDSA is encouraging all HD impacted families to consider getting involved.

As 2014 comes to a close, we hope that you will see in the latest edition of our Research Investor’s Report that HDSA and the research community have made tremendous progress towards meaningful clinical trials that will hopefully modify the course of HD and bring relief and hope to you — our HD families.

COMMUNITY INVOLVEMENT

In 2014, volunteer-led events, big and small, brought together local communities in almost every state to raise awareness, fund the mission of HDSA, and to provide help for today, hope for tomorrow for our HD community.

HDSA’s signature fundraising campaign, Team Hope, raised nearly $2 million dollars with approximately 18,000 participants in 98 Team Hope Walks across the country. While, other popular events such as Celebrations of Hope, Hoop-A-Thons and educational events raised hundreds of thousands of dollars for HDSA’s mission. The HDSA New York City Marathon Team which consisted of 20 runners from across the country raised more than $80,000.
ADVOCACY

Huntington’s Disease Parity Act (HR1015/S723): Re-introduced by Rep. Bill Pascrell (D-NJ) and Adam Kinzinger (R-IL) in the 113th Congress that convened in January 2013 and ended in December 2014. The Huntington’s Disease Parity Act is legislation that will compel the Social Security Administration (SSA) to revise their outdated neurological listings for HD as well as waive the two year waiting period for Medicare once a person is deemed disabled. During the 113th Congress, our advocates worked tirelessly to secure co-sponsorship by their elected representatives. Thanks to their effort, the Huntington’s Disease Parity Act ended with 189 co-sponsors in the House and 13 in the Senate.

During 2014, the National Youth Alliance came out as strong advocates for the Parity Act, using fly-ins to Washington DC as an opportunity to give a face and a voice to HD on Capitol Hill. Thanks to their efforts, 22 co-sponsors were added to the Parity Act.

Social Security Administration

In February, SSA released their revisions to the proposed neurological listings. The new listings continue to fail to address the cognitive and behavioral aspects of HD. Motor symptoms remain the definitive criteria for disability. In response, HDSA submitted comments to SSA and called upon the HD community to also send a message to SSA. Our community sent 567 messages to SSA during their open comment period - by far the largest number SSA received from any group – while 20 PREDICT-HD investigators signed a letter directed to SSA on their failure to include the cognitive and behavioral symptoms of HD in the new listings. HDSA continues to monitor the roll out of the proposed neurological listings which currently remain on hold.

HDSA participated in a teleconferenced meeting with SSA in May. During the hour long session, HDSA asked pertinent questions regarding the review process, timeline for implementation and revisions to current CAL listings for HD. HDSA was the only group to ask questions during the session and to submit additional comments immediately following the teleconference.

HDSA presented posters on our efforts to work with SSA to reduce denials and delays for persons with HD seeking disability at both the annual Huntington Study Group and NORD meetings.

U.S. Food and Drug Administration (FDA)

HDSA also launched two community wide surveys in the fall in anticipation of the Patient Focused Drug Development meeting for HD that the FDA will convene in 2015. More than 2500 HD family members completed the survey on symptoms while more than 1000 responded to the survey on treatment options. The survey results will be presented to FDA at the meeting and will help to inform them of the needs of the HD community at large in the areas of potential treatments and symptom management.
## Statement of Financial Position

**AS OF DECEMBER 31, 2014 AND 2013**

<table>
<thead>
<tr>
<th>ASSETS</th>
<th>2014</th>
<th>2013</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cash and cash equivalents</td>
<td>3,617,512</td>
<td>3,039,561</td>
</tr>
<tr>
<td>Investments, at fair value</td>
<td>264,773</td>
<td>563,280</td>
</tr>
<tr>
<td>Pledges and contributions receivable, net</td>
<td>1,145,369</td>
<td>699,008</td>
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<tr>
<td>Other receivables</td>
<td>214,806</td>
<td>0</td>
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<tr>
<td>Prepaid expenses and deposits</td>
<td>113,203</td>
<td>120,502</td>
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<td>Cash surrender value of life insurance</td>
<td>0</td>
<td>129,271</td>
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<tr>
<td>Property and equipment, net</td>
<td>36,595</td>
<td>49,728</td>
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<tr>
<td><strong>Total Assets</strong></td>
<td><strong>5,392,258</strong></td>
<td><strong>4,601,350</strong></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>LIABILITIES</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Accounts payable and accrued expenses</td>
<td>89,542</td>
<td>180,566</td>
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<tr>
<td>Accrued compensation</td>
<td>188,935</td>
<td>175,379</td>
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<tr>
<td>Research grants payable</td>
<td>1,237,883</td>
<td>1,547,370</td>
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<td>Deferred rent</td>
<td>18,894</td>
<td>53,270</td>
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<tr>
<td>Obligation under capital lease</td>
<td>9,773</td>
<td>15,942</td>
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<tr>
<td>Deferred revenue</td>
<td>39,867</td>
<td>10,945</td>
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<tr>
<td><strong>Total Liabilities</strong></td>
<td><strong>1,584,894</strong></td>
<td><strong>1,983,472</strong></td>
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</table>

<table>
<thead>
<tr>
<th>NET ASSETS</th>
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</thead>
<tbody>
<tr>
<td>Unrestricted</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Undesignated</td>
<td>(548,687)</td>
<td>(1,066,803)</td>
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<tr>
<td>Board-designated</td>
<td>511,664</td>
<td>510,152</td>
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<tr>
<td>Temporarily restricted</td>
<td>3,594,387</td>
<td>2,924,529</td>
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<tr>
<td>Permanently restricted</td>
<td>250,000</td>
<td>250,000</td>
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<tr>
<td><strong>Total Net Assets</strong></td>
<td><strong>3,807,364</strong></td>
<td><strong>2,617,878</strong></td>
</tr>
</tbody>
</table>

**Total Liabilities And Net Assets**                  | **5,392,258** | **4,601,350**

**NOTE:** These Consolidated Statements reflect HDSA’s operations for the fiscal years as stated and include all affiliates. Please contact the National Office for a full copy of the audited financial statements.
## Consolidated Statement of Activities

**FOR THE YEARS ENDED DECEMBER 31, 2014 AND 2013**

### SUPPORT & REVENUE

<table>
<thead>
<tr>
<th>Description</th>
<th>2014</th>
<th>2013</th>
</tr>
</thead>
<tbody>
<tr>
<td>Public donations</td>
<td>3,104,819</td>
<td>2,663,792</td>
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<tr>
<td>Foundation grants and corporate contributions</td>
<td>1,253,962</td>
<td>1,472,230</td>
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<tr>
<td>Federal campaign</td>
<td>280,164</td>
<td>286,049</td>
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<tr>
<td>Investment income</td>
<td>5,173</td>
<td>12,022</td>
</tr>
<tr>
<td>Life insurance proceeds</td>
<td>85,535</td>
<td>0</td>
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<tr>
<td>Donated services</td>
<td>412,872</td>
<td>187,265</td>
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<tr>
<td>Other</td>
<td>28,756</td>
<td>24,485</td>
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<tr>
<td><strong>Total Support and Revenue</strong></td>
<td>5,171,281</td>
<td>4,635,843</td>
</tr>
</tbody>
</table>

### EXPENSES

**Program services:**

<table>
<thead>
<tr>
<th>Description</th>
<th>2014</th>
<th>2013</th>
</tr>
</thead>
<tbody>
<tr>
<td>Research</td>
<td>1,643,133</td>
<td>1,207,444</td>
</tr>
<tr>
<td>Community services</td>
<td>2,079,052</td>
<td>2,145,314</td>
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<tr>
<td>Education</td>
<td>1,239,835</td>
<td>1,532,395</td>
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<tr>
<td>Chapter development</td>
<td>936,040</td>
<td>1,056,693</td>
</tr>
<tr>
<td><strong>Total Program</strong></td>
<td>5,898,060</td>
<td>5,941,846</td>
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</tbody>
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**Supporting services:**

<table>
<thead>
<tr>
<th>Description</th>
<th>2014</th>
<th>2013</th>
</tr>
</thead>
<tbody>
<tr>
<td>Management and general</td>
<td>929,721</td>
<td>817,947</td>
</tr>
<tr>
<td>Fundraising</td>
<td>957,100</td>
<td>1,120,500</td>
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<tr>
<td><strong>Total Supporting</strong></td>
<td>1,886,821</td>
<td>1,938,447</td>
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</table>

**Total Expenses**

<table>
<thead>
<tr>
<th>Description</th>
<th>2014</th>
<th>2013</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total Expenses</strong></td>
<td>7,784,881</td>
<td>7,880,293</td>
</tr>
</tbody>
</table>

**Change in net assets before non-operating income**

<table>
<thead>
<tr>
<th>Description</th>
<th>2014</th>
<th>2013</th>
</tr>
</thead>
<tbody>
<tr>
<td>Change in net assets before non-operating</td>
<td>(2,613,600)</td>
<td>(3,244,450)</td>
</tr>
</tbody>
</table>

**Non-operating income:**

**Special events:**

<table>
<thead>
<tr>
<th>Description</th>
<th>2014</th>
<th>2013</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gross receipts</td>
<td>4,481,670</td>
<td>4,108,409</td>
</tr>
<tr>
<td>Less: direct costs</td>
<td>(678,584)</td>
<td>(705,474)</td>
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<tr>
<td><strong>Net income from special events</strong></td>
<td>3,803,086</td>
<td>3,402,935</td>
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</tbody>
</table>

**Change in Net Assets**

<table>
<thead>
<tr>
<th>Description</th>
<th>2014</th>
<th>2013</th>
</tr>
</thead>
<tbody>
<tr>
<td>Change in Net Assets</td>
<td>1,189,486</td>
<td>158,485</td>
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</tbody>
</table>

**Net assets - beginning of year**

<table>
<thead>
<tr>
<th>Description</th>
<th>2014</th>
<th>2013</th>
</tr>
</thead>
<tbody>
<tr>
<td>Net assets - beginning of year</td>
<td>2,617,878</td>
<td>2,459,393</td>
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</tbody>
</table>

**Net Assets - December 31**

<table>
<thead>
<tr>
<th>Description</th>
<th>2014</th>
<th>2013</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Net Assets - December 31</strong></td>
<td>3,807,364</td>
<td>2,617,878</td>
</tr>
</tbody>
</table>

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HDSA is proud to report that in 2014, 76% of funds raised goes directly to its mission to improve the lives of everyone affected by Huntington’s disease.
HDSA Leadership

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Senior Director
Mission & Scientific Affairs

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Director of Financial & Administrative Management

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Director of Marketing & Communications

Nancy A. Rhodes
Director of Field Development & Operations
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Scott & Janet Hamilton
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Lisa Happee
Harold Harden
Tony Hartling
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Joel Kingerly
John Klarer
William & Marguerite Kline
Roland Klober
Sarah Knowles
Denise Korcal
Sandra Kostyk
Frank Krasovec
Kersti Krepp
Ted & Carla Krull
David Krumholtz
Douglas N. LaBelle
Tami Lack
Ernest Lahusky
Gary & Teresa Lamb
Wayne Langen
Niels Larson
Frank Lauck
Jeanne Layhee
Maureen Leary
Pamela Lederer
Ron Lee
John Legere
George Letchworth
David & Sophia Leung
William Levy
Mark Leyton
Joseph Lieb
Evelyn Lieberman
Phillip & Eva Lindsey
Carol Lopez
Kristy Lopresit
Annette Luckow
Jeanette Lynah
Bridget Tare Lynch
Estella P. Lyon
R.D. Lyon
James Mamer
William S. Mosakowski
Bradley Moser
Katharine Moser
Nicole Moser
Michael Moses
Sharmin Mossavar-Rahmani
Gertrude H. Marvin
Nima Massoomi
Tim Mathews
Nicole Mawby
Joel Maxfield
Doria J. Mayer
William McAdam
Karen McClaran
Leslie McCormick
Michael McCoy
Anne McErlelon
Casey McGlynn
Jack McGrory
James M. McNamara
Terri McSpadden
Arnold & Harriet Meier
Sandra Methot
David Miles
Jonathan Stephen Miller
Lynette Miller
Peggy A. Miller
Robert Millum
Chris Misner
James Mislzer
Robert Moore
John Moors
Chad Morton
William S. Mosakowski
Bradley Moser
Katharine Moser
Nicole Moser
Michael Moses
Sharmin Mossavar-Rahmani
Mark Murphy
Nina Nakayama
Martha Nance, M.D.
Betty Neese
Michael I. Neil
Joe & Pam Nemec
Jojo Neumann
Nancy Newbould
William Newman
Ethelyn M. Newton
John R. Oakland
Joan M. O’Donnell-Starcevich
Mark Oldfield
Mary O’Malley
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Matthew Poole
Theodore Posner
Jennifer Pratt
Jeanine Prichard
Steve & Sharon Primeau
Dean Prober
Beth Prochaska
Chris Pundzak
Pamela J. Pyle
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Leslie Rich
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Abhay Risbud
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Ted Ross
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