“From awareness and advocacy to community support and research, 2016 was an extraordinary year for the Huntington’s Disease Society of America. We were able to provide more assistance, fund more science and ensure more world-leading resources to families affected by Huntington’s disease than ever before. This is all possible thanks to the tireless work of HDSA volunteers and advocates across the country. Thank you for all your dedication and support in the fight against HD!”

LOUISE VETTER
PRESIDENT & CHIEF EXECUTIVE OFFICER
HDSA Research Grant Programs

In November 2016, the Huntington’s Disease Society of America announced that nine research grants have been awarded under the Society’s largest research initiative, the HDSA Huntington’s Disease Human Biology Project. Totaling $930,000, these grants represent HDSA’s patient-centric research focus which brings basic and clinical researchers together to facilitate Huntington’s disease science in the human condition, instead of in animal models, with the direct participation of people affected by Huntington’s disease.

In May of 2016, HDSA announced that Dr. Ricardo Mouro Pinto of Massachusetts General Hospital/Harvard Medical School had been awarded the inaugural HDSA Berman-Topper Family HD Career Development Fellowship.

This prestigious new fellowship, made possible due to generosity of the Berman and Topper families, provides up to $80,000 of funding per year for three years to young scientists and clinicians who desire to make Huntington’s disease (HD) part of their long-term career plan. Dr. Pinto’s project is officially titled “Identification of genetic modifiers of somatic CAG instability in Huntington’s disease by in-vivo CRISPR-cas9 genome editing.”

The Guthrie Sessions at HDSA

This year HDSA launched The Guthrie Sessions at HDSA to pay homage to our music roots and the Guthrie family legacy. The performances are edited and directed by Rae Maxwell and have received fabulous fanfare.

Artists volunteer their time and talents to support HDSA’s mission and pay tribute to Woody Guthrie. Every Monday, a new song from a monthly featured artist is released on the HDSA YouTube Channel and shared across HDSA’s social media platforms. The program has reached thousands — introducing HD to new audiences around the globe. Tune in at HDSA.org/GuthrieSessions.

#LetsTalkAboutHD

HDSA turned up the global volume on Huntington’s disease awareness by launching the incredibly successful #LetsTalkAboutHD campaign during HD Awareness Month in May. The viral social media initiative featured daily celebrity videos, family stories, photos and infographics discussing the devastating impact of Huntington’s disease.

Celebrity support included: Mario Lopez, Scott Porter, Drew Brees, Joe Smith, the L.A. Angels, Vincent Piazza, Lisa Genova, Jake Dowell, Jerrod Niemann and many more!

Betty Who performing at The Guthrie Sessions at HDSA.
Events

**Team Hope Walk Program**
Thanks to the INCREDBLIBLE work of HDSA’s volunteer-led 54 Chapters and Affiliates across the country, HDSA’s signature Team Hope walk program had a record year raising $2.3 million and registered 16,000 walkers in 2016!

Second Annual Freeze HD Event
The stars came out on September 24th, 2016 at the Bootleg Theater in Los Angeles to raise funds and awareness at the Second Annual Freeze HD event. More than $200,000 was raised to support HDSA and HDBuzz. Among the many special guests in attendance were actresses Annette Bening and Marianna Palka as well as Jason, Tyler, Carly and Nancy Ritter. The event was coordinated by actress Kate Miner and her family. Kate’s mother and two sisters have tested positive for HD and have become incredible advocates in raising HD awareness and funds to support HDSA’s mission. The event also included special musical performances from Moon Child and Zac Clark.

**31st Annual HDSA Convention**
The Huntington’s Disease Society of America welcomed nearly 930 guests to the 31st Annual HDSA Convention in Baltimore, Maryland. Held at the Hyatt Regency Inner Harbor, the three-day event took place June 2nd thru 4th and was the second most attended Convention in the organization’s history. The vast majority of attendees were individuals from Huntington’s disease families, but they were joined by a global roster of researchers, social workers, clinicians, volunteers and advocates.

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Advocacy

**Huntington’s Disease Parity Act**
2016 was a banner year for Advocacy! Advocates from all corners of the HD community got engaged in the effort to pass the Huntington’s Disease Parity Act and to see positive changes for families affected by Huntington’s disease. We saw major victories in 2016, including the release and implementation of new guidelines for HD by the Social Security Administration (SSA).

**FDA Approves Drug Review for HD Treatment**
HDSA advocates came out in force to tell the Food and Drug Administration that we need new treatments for HD. In just over one month, almost 4,000 members of the HD Community signed their names and told their stories in a petition asking the FDA to allow SD-809 a speedy and community-focused review. As a result, the FDA has accepted a new review of the drug with priority status.

Recognition

**HDSA Receives Highest Ratings**
In late 2016 it was announced that the Huntington’s Disease Society of America once again achieved Top-Rating status from CharityWatch and a Four-Star rating from Charity Navigator. “Thanks to the hard work and vigilance of the HD Community we are honored to uphold these high standards,” said Louise Vetter, HDSA President & CEO.
### ASSETS

<table>
<thead>
<tr>
<th>Description</th>
<th>2016</th>
<th>2015</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cash and cash equivalents</td>
<td>5,682,692</td>
<td>4,537,268</td>
</tr>
<tr>
<td>Investments, at fair value</td>
<td>496,158</td>
<td>425,792</td>
</tr>
<tr>
<td>Pledges and contributions receivable, net</td>
<td>905,233</td>
<td>1,175,028</td>
</tr>
<tr>
<td>Prepaid expenses and deposits</td>
<td>146,050</td>
<td>144,645</td>
</tr>
<tr>
<td>Property and equipment, net</td>
<td>50,747</td>
<td>45,608</td>
</tr>
<tr>
<td><strong>Total Assets</strong></td>
<td><strong>7,280,860</strong></td>
<td><strong>6,268,321</strong></td>
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### LIABILITIES

<table>
<thead>
<tr>
<th>Description</th>
<th>2016</th>
<th>2015</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accounts payable and accrued expenses</td>
<td>120,396</td>
<td>220,345</td>
</tr>
<tr>
<td>Research grants payable</td>
<td>1032,367</td>
<td>540,161</td>
</tr>
<tr>
<td>Deferred rent</td>
<td>93,118</td>
<td>72,116</td>
</tr>
<tr>
<td>Obligation under capital lease</td>
<td>21,331</td>
<td>2,626</td>
</tr>
<tr>
<td>Deferred revenue</td>
<td>31,254</td>
<td>34,010</td>
</tr>
<tr>
<td><strong>Total Liabilities</strong></td>
<td><strong>1,055,485</strong></td>
<td><strong>1,156,493</strong></td>
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</tbody>
</table>

### NET ASSETS

<table>
<thead>
<tr>
<th>Description</th>
<th>2016</th>
<th>2015</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unrestricted</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Undesignated</td>
<td>1,047,104</td>
<td>204,517</td>
</tr>
<tr>
<td>Board-operating reserve</td>
<td>932,251</td>
<td>686,827</td>
</tr>
<tr>
<td><strong>Total Net Assets</strong></td>
<td><strong>5,725,375</strong></td>
<td><strong>5,349,628</strong></td>
</tr>
</tbody>
</table>

### SUPPORT & REVENUE

<table>
<thead>
<tr>
<th>Description</th>
<th>2016</th>
<th>2015</th>
</tr>
</thead>
<tbody>
<tr>
<td>Public donations</td>
<td>2,245,579</td>
<td>2,813,624</td>
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<tr>
<td>Foundation grants and corporate contributions</td>
<td>1,749,617</td>
<td>1,946,638</td>
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<tr>
<td>Federal campaign</td>
<td>303,133</td>
<td>289,481</td>
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<tr>
<td>Investment income</td>
<td>11,170</td>
<td>7,665</td>
</tr>
<tr>
<td>Donated services and materials</td>
<td>301,028</td>
<td>539,333</td>
</tr>
<tr>
<td>Other</td>
<td>5,883</td>
<td>22,913</td>
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<tr>
<td><strong>Total Support and Revenue</strong></td>
<td><strong>4,618,410</strong></td>
<td><strong>5,619,264</strong></td>
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</tbody>
</table>

### EXPENSES

<table>
<thead>
<tr>
<th>Description</th>
<th>2016</th>
<th>2015</th>
</tr>
</thead>
<tbody>
<tr>
<td>Research</td>
<td>1,959,619</td>
<td>1,727,027</td>
</tr>
<tr>
<td>Family services</td>
<td>2,275,034</td>
<td>1,949,944</td>
</tr>
<tr>
<td>Education</td>
<td>1,540,144</td>
<td>1,553,769</td>
</tr>
<tr>
<td>Chapter development</td>
<td>1,024,045</td>
<td>1,014,816</td>
</tr>
<tr>
<td><strong>Total Expenses</strong></td>
<td><strong>8,935,104</strong></td>
<td><strong>8,307,311</strong></td>
</tr>
</tbody>
</table>

### Totals

<table>
<thead>
<tr>
<th>Description</th>
<th>2016</th>
<th>2015</th>
</tr>
</thead>
<tbody>
<tr>
<td>Change in net assets before non-operating income</td>
<td><strong>(4,316,694)</strong></td>
<td><strong>(2,688,047)</strong></td>
</tr>
<tr>
<td>Non-operating income:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Special events:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gross receipts</td>
<td>5,456,354</td>
<td>4,628,925</td>
</tr>
<tr>
<td>Less: direct costs</td>
<td>(564,193)</td>
<td>(598,394)</td>
</tr>
<tr>
<td><strong>Net income from special events</strong></td>
<td><strong>4,892,241</strong></td>
<td><strong>4,030,511</strong></td>
</tr>
<tr>
<td>Increase in Net Assets</td>
<td>575,547</td>
<td>1,342,464</td>
</tr>
<tr>
<td>Net assets - beginning of year</td>
<td>5,149,828</td>
<td>3,807,364</td>
</tr>
<tr>
<td><strong>Net Assets - December 31</strong></td>
<td><strong>5,725,375</strong></td>
<td><strong>5,349,628</strong></td>
</tr>
</tbody>
</table>

### Notes

- These Consolidated Statements reflect HDSA’s operations for the fiscal years as stated and include all affiliates. Please contact the HDSA National Office for a full copy of the audited financial statements.
Your HDSA Dollars at Work

**OVERVIEW**

- **TOTAL 2016 REVENUE**
  - $10,074,764
- **INCREASE IN NET ASSETS**
  - $575,547
- **FUNDED HDSA CENTERS OF EXCELLENCE AND RESEARCH PROGRAMS**
  - $2,329,769

**Funds Allocation**

- **Program Services**
  - 76%
- **Fundraising**
  - 15%
- **Management**
  - 12%

- **Chapter Development**
  - 15%
- **Family Services**
  - 23%
- **Education**
  - 29%
- **Research**
  - 33%

**76% of all funds are allocated to program services**

---

**HDSA Leadership**

**HDSA National Board of Trustees**

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  - Chair
  - Los Angeles, CA
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  - Chair Elect
  - Olympia, WA
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  - Riverside, CT
- **Jennifer Leyton**
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- **Donald Higgins, M.D.**
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- **Bill Kline**
  - Eatonton, GA
- **Michael Roth**
  - New York, NY
- **Arvind Sreedharan**
  - Chicago, IL
- **Victor Sung, M.D.**
  - Birmingham, AL

**Senior Staff**

- **Louise A. Vetter**
  - President and Chief Executive Officer
- **George Yohrling, Ph.D.**
  - Senior Director Mission & Scientific Affairs
- **Nadene Alleyne**
  - Director of Financial & Administrative Management
- **Christopher Cosentino**
  - Director of Marketing & Communications
- **Nancy A. Rhodes**
  - Director of Field Development & Operations
Thank You!

Thank You to Our Donors
For Their Generous Support
Thank You!

Thank You to the Following Corporations and Foundations for Their Generous Support

$50,000+
Charles Schwab Foundation
Community Health Charities
The Gies Foundation
The Griffin Adult Down Syndrome Services, Inc.
Charles Schwab
TouchBionics, Inc.
Western Wall and Ceiling Contractors Association, Inc.

$49,999 - $25,000
American Legion Child Welfare Foundation
The Benevity Community Fund
Lundbeck, Inc.

MassMutual
Walter J. & Betty C. Zable Foundation
Western Wall and Ceiling Contractors Association, Inc.

$24,999 - $10,000
A.A. Will Corporation
Barlow Haygle Foundation Fund
Charitable Adult Rides & Services, Inc.
Charles Schwab
ConocoPhillips Company
Fred Barronov

C.G.B. Foundation
Guthrie Foundation

$19,999 - $5,000
Allstate Foundation
Cleveland Clinic
Employees Community Fund of Boeing

$14,999 - $5,000
American Legion Auxiliary
Arkansas Blue Cross Blue Shield

$14,999 - $1,000
AT&T Companies
Alberici Constructors
The Albertsons Companies Foundation
The Allegheny Foundation
Aly Financial Inc.
Amazon Smile Foundation
American Investment Co.
American Legion Auxiliary
APC Workforce Solutions II, LLC
Apollo Rehab Care Center
Anchor Pharmaceuticals, LLC
AvalonMiltal Matching Gifts Program
Argus Corporation
Arkansas Blue Cross Blue Shield

Arm Group Inc.
The Ashton Company, Inc.
B & D Thread Railing, Inc.
The Bank of America Charitable Foundation
Bank of America Employee Giving Campaign
Berkeley Hallaway HomeServices
Bill & Melinda Gates Foundation
Board of Education, School District No. 1
The Boeing Company
Breakerside Community Schools
Bright Funds Foundation
Buffalo Bisons, LLC
C.C. Hodgkin Architectural Group
C.H. Evans Brewing Co. Inc.
Carnival Cruise Line
Case Western Reserve University
Central Indiana Community Foundation
Certified Blue Plumbing, LLC
Chargers Charities
Charles T. Stihl Health Care Center, Inc.
Chiara Foundation

$1,000
Christ Church Pompton Lakes, NJ
Charles T. Sitrin Health Care Center, Inc.
Chargers Charities
Certified Blue Plumbing, LLC
Chargers Charities
Charles T. Stihl Health Care Center, Inc.
Chiara Foundation

$500
Chesapeake Energy Foundation
Chesapeake Energy Foundation

$250
Chesapeake Energy Foundation
Chesapeake Energy Foundation

$100
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Chesapeake Energy Foundation

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Chesapeake Energy Foundation

$2
Chesapeake Energy Foundation
Chesapeake Energy Foundation

$1
Chesapeake Energy Foundation
Chesapeake Energy Foundation
As promising clinical trials move us closer to potentially game-changing cures and treatments, HD families across the country still require access to the crucial research, care, and advocacy programs that HDSA provides.

Our Planned Giving program ensures that HDSA has the resources to continue providing help and hope to the HD community as long as it is in need. By including HDSA in your will as a recipient of estate, insurance, stock, and/or retirement plan gifts, you can create a legacy of giving that will guarantee that future generations have the vital support necessary to confront this devastating illness. Among the many benefits of Planned Giving is the fact that the proceeds from an estate or asset can sometimes allow individuals to actually contribute more toward programs than they might be able to give in their lifetime. With the help of a financial planner, Planned Giving donors can arrange their gift in a way that ensures that, after taxes, the largest possible sum can have the strongest possible impact on the lives of those affected by HD in the decades to come.

For more information about Planned Giving at HDSA, please contact Assistant Director of Major and Individual Giving Jon Hogan at 212.242.1968 ext. 232 or jhogan@hdsa.org.

Every year at HDSA’s Convention, the Blue Light Ceremony is held in honor of those who have succumbed to Huntington’s disease.

We are grateful for the gifts from the following estates who helped make our work possible in 2016.

- Estate of Barbara L. Bell
- Estate of Susan Caldwell
- Estate of Charlotte F. Calhoun
- Estate of Dean Gleckler
- Estate of Katrin Heidelmeier
- Estate of Jeanette D. Hersey
- Estate of Gary J. Hull
- Estate of Earl J. Jackson
- Estate of Thomas B. Johnson
- Estate of Wilma M. Jones
- Estate of Martha Sanders King
- Estate of Deborah Light
- Estate of Norma E. Novak
- Estate of Dorothy Schwope
Our Mission:
To improve the lives of people with Huntington’s disease and their families.

Our Vision:
A world free of Huntington’s disease.
HUNTINGTON’S DISEASE
SOCIETY OF AMERICA
505 Eighth Avenue
Suite 902
New York, NY 10018

212 242 1968
Helpline: 800 345 HDSA
Email: hdsainfo@hdsa.org

www.hdsa.org