



*Help for Today, Hope for Tomorrow.*

**FAMILY**  
*is everything.*



# 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 **29<sup>th</sup> 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,

A handwritten signature in black ink that reads "Jang-Ho Cha".

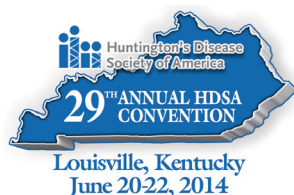
**Jang-Ho Cha, M.D., Ph.D.**  
Chair, Board of Trustees

A handwritten signature in black ink that reads "Louise Vetter".

**Louise Vetter**  
Chief Executive Officer

# 2014 Year In Review

## 29<sup>TH</sup> ANNUAL CONVENTION IN LOUISVILLE



The Huntington's Disease Society of America hosted the **29<sup>th</sup> Annual Convention** at the Galt House in Louisville, KY on July 20<sup>th</sup>-22<sup>nd</sup>. 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

	2014	2013
<b>ASSETS</b>		
Cash and cash equivalents	3,617,512	3,039,561
Investments, at fair value	264,773	563,280
Pledges and contributions receivable, net	1,145,369	699,008
Other receivables	214,806	0
Prepaid expenses and deposits	113,203	120,502
Cash surrender value of life insurance	0	129,271
Property and equipment, net	36,595	49,728
<b>Total Assets</b>	<b>5,392,258</b>	<b>4,601,350</b>
<b>LIABILITIES</b>		
Accounts payable and accrued expenses	89,542	180,566
Accrued compensation	188,935	175,379
Research grants payable	1,237,883	1,547,370
Deferred rent	18,894	53,270
Obligation under capital lease	9,773	15,942
Deferred revenue	39,867	10,945
<b>Total Liabilities</b>	<b>1,584,894</b>	<b>1,983,472</b>
<b>NET ASSETS</b>		
<b>Unrestricted</b>		
Undesignated	(548,687)	(1,066,803)
Board-designated	511,664	510,152
	(37,023)	(556,651)
<b>Temporarily restricted</b>	3,594,387	2,924,529
<b>Permanently restricted</b>	250,000	250,000
<b>Total Net Assets</b>	<b>3,807,364</b>	<b>2,617,878</b>
<b>Total Liabilities And Net Assets</b>	<b>5,392,258</b>	<b>4,601,350</b>

**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.

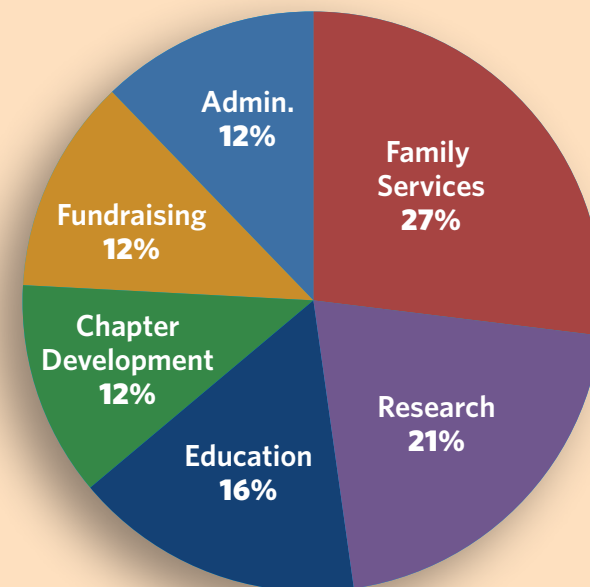
# Consolidated Statement of Activities

FOR THE YEARS ENDED DECEMBER 31, 2014 AND 2013

	2014	2013
<b>SUPPORT &amp; REVENUE</b>		
Public donations	3,104,819	2,653,792
Foundation grants and corporate contributions	1,253,962	1,472,230
Federal campaign	280,164	286,049
Investment income	5,173	12,022
Life insurance proceeds	85,535	0
Donated services	412,872	187,265
Other	28,756	24,485
<b>Total Support and Revenue</b>	<b>5,171,281</b>	<b>4,635,843</b>
<b>EXPENSES</b>		
<b>Program services:</b>		
Research	1,643,133	1,207,444
Community services	2,079,052	2,145,314
Education	1,239,835	1,532,395
Chapter development	936,040	1,056,693
	<b>5,898,060</b>	<b>5,941,846</b>
<b>Supporting services:</b>		
Management and general	929,721	817,947
Fundraising	957,100	1,120,500
	<b>1,886,821</b>	<b>1,938,447</b>
<b>Total Expenses</b>	<b>7,784,881</b>	<b>7,880,293</b>
Change in net assets before non-operating income	(2,613,600)	(3,244,450)
<b>Non-operating income:</b>		
Special events:		
Gross receipts	4,481,670	4,108,409
Less: direct costs	(678,584)	(705,474)
<b>Net income from special events</b>	<b>3,803,086</b>	<b>3,402,935</b>
Change in Net Assets	1,189,486	158,485
Net assets - beginning of year	2,617,878	2,459,393
<b>Net Assets - December 31</b>	<b>3,807,364</b>	<b>2,617,878</b>

## HDSA DOLLARS AT WORK

Fiscal Year 2014 Functional Expenses



76%

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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 Boeing Employees Community Fund of California  
 BT Cisterra Investors LLC  
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 The Benevity Community Impact Fund  
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 Charitable Adult Rides & Services, Inc.  
 Central Indiana Community Foundation  
 Cymer, Inc.  
 Kohls  
 Michigan Gaming Control Board  
 Microsoft Matching Gifts Program  
 National Insurance Services  
 Network For Good  
 Qualcomm Matching Grant Program  
 Raptor Pharmaceuticals  
 The GE Foundation  
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#### **\$50,000+**

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 Community Health Charities  
 Lundbeck Inc.  
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# HDSA Heritage Club

A variety of generous donors make possible the Huntington's Disease Society of America's programs and services for the HD community. Individuals, corporations, and foundations are all crucial partners in ensuring that — each year — we offer vital care, research, and advocacy services.

**HDSA's Heritage Club** is an excellent way to guarantee that the organization has the resources it needs to continue fighting the disease until the day it is eradicated. Naming HDSA as the beneficiary of an estate, insurance, stock,

and/or retirement plan is a great way to make an investment of any size in the future of the HD community, with a Planned Gift often giving the opportunity to make a greater contribution than can be made in one's lifetime. It's never too early to create a legacy of support for those affected by HD with estate planning. A Planned Gift made today will bolster our work in the future.

**For more information about Planned Giving at HDSA, please contact Assistant Director of Individual Giving Jon Hogan at 212.242.1968 ext. 232 or [jhogan@hdsa.org](mailto:jhogan@hdsa.org).**

## *Special Thanks*

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Estate of Patricia A. Bauman

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Estate of Barbara L. Bell

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Estate of Charlotte F. Calhoun

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Estate of Claire Campbell

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Estate of Dean Gleckler

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Estate of Dale Hach

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Estate of John Heidelmeier

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Estate of Norma E. Novak

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Estate of Helen B. Rostetter

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Estate of Jerry Setten

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Estate of Edith Weiner

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Huntington's Disease  
Society of America

**HUNTINGTON'S DISEASE  
SOCIETY OF AMERICA**

505 Eighth Avenue  
Suite 902  
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*Help for Today, Hope for Tomorrow.*

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[hdsainfo@hdsa.org](mailto:hdsainfo@hdsa.org)

**OUR VISION:** *A world free of Huntington's disease.*

**OUR MISSION:** *To improve the lives of people with  
Huntington's disease and their families.*

