





“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

2016 Highlights

Support

HDSA Expands Centers of Excellence Program

In 2016, the HDSA Centers of Excellence program expanded to 39 Centers from 29 in 2015 — a 25% increase in the reach of the program. The HDSA



Centers of Excellence share an exemplary commitment to bringing more comprehensive care to more HD affected families across the United States and will have more ‘boots on the ground’ with locations in 30 US states. HDSA allocated \$1,092,250 to the Centers of Excellence program which is a 38 percent increase in funding from the \$790,000 awarded in 2015.

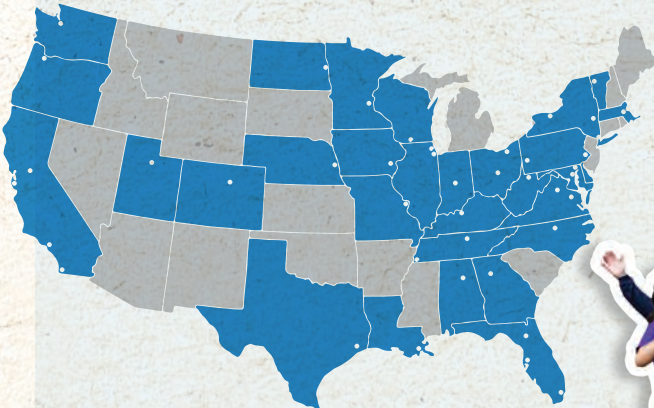


HDSA Provides 1,000 Free Liftware Level Devices

The Huntington’s Disease Society of America , in partnership with **Teva Pharmaceuticals**, launched a program that provides 1,000 free Liftware Level Starter Kits to HD families in need. Liftware Levels help people with limited hand and arm mobility hold a utensil at the angle needed to eat more easily.

NYA Keeps Growing!

HDSA’s National Youth Alliance (NYA) grew leaps and bounds! For the first time ever, the NYA hosted multiple youth programming events around the country. The NYA hosted three NYA Regional Youth Retreats in 2016 in collaboration with local Chapters and HDSA Centers of Excellence. With funding from Teva Pharmaceuticals, the National Youth Alliance held free, day-long retreats in Pittsburgh, Iowa City and Denver, bringing 42 young people together to laugh, learn, and feel connected to other young people affected by this terrible disease



Education



World Leader in HD Education

HDSA had a busy year developing educational programs for both our allied healthcare professionals and our HD families. For our healthcare professionals, HDSA launched a five part cooperative continuing education program with the American Physical Therapy Association/Neurology Division (APTA) in December 2015 to educate community based physical therapists.

Additionally, HDSA launched a four part continuing education course for community based occupational therapists in partnership with the American Occupational Therapy Association (AOTA) in order to educate community based occupational therapists on what they needed to know about HD in order to assess and treat persons with HD in their communities.

Research

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**. Totalling \$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.*"



Awareness



#LetsTalkAboutHD

#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!

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**.



Betty Who performing at the Guthrie Sessions at HDSA.

Events



Team Hope Walk Program

Thanks to the INCREDIBLE 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.



Above: HDSA's Chairman, Dr. Jang-Ho Cha and Chief Executive Officer, Louise Vetter, present Woody Guthrie Advocacy Awards to members of the HDSA National Youth Alliance Advocacy Board.

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.



Statements of Financial Position

AS OF DECEMBER 31, 2016 AND 2015

	2016	2015
ASSETS		
Cash and cash equivalents	5,682,692	4,537,268
Investments, at fair value	496,158	425,792
Pledges and contributions receivable, net	905,233	1,115,008
Prepaid expenses and deposits	146,030	144,645
Property and equipment, net	50,747	45,608
Total Assets	7,280,860	6,268,321
LIABILITIES		
Accounts payable and accrued expenses	120,396	220,345
Accrued compensation	257,019	249,235
Research grants payable	1,032,367	540,161
Deferred rent	93,118	72,116
Obligation under capital lease	21,331	2,626
Deferred revenue	31,254	34,010
Total Liabilities	1,555,485	1,118,493
NET ASSETS		
Unrestricted		
Undesignated	1,047,304	204,517
Board-operating reserve	932,251	686,827
	1,979,555	891,344
Temporarily restricted	3,495,820	4,008,484
Permanently restricted	250,000	250,000
Total Net Assets	5,725,375	5,149,828
Total Liabilities And Net Assets	7,280,860	6,268,321

NOTE: 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.

Consolidated Statement of Activities

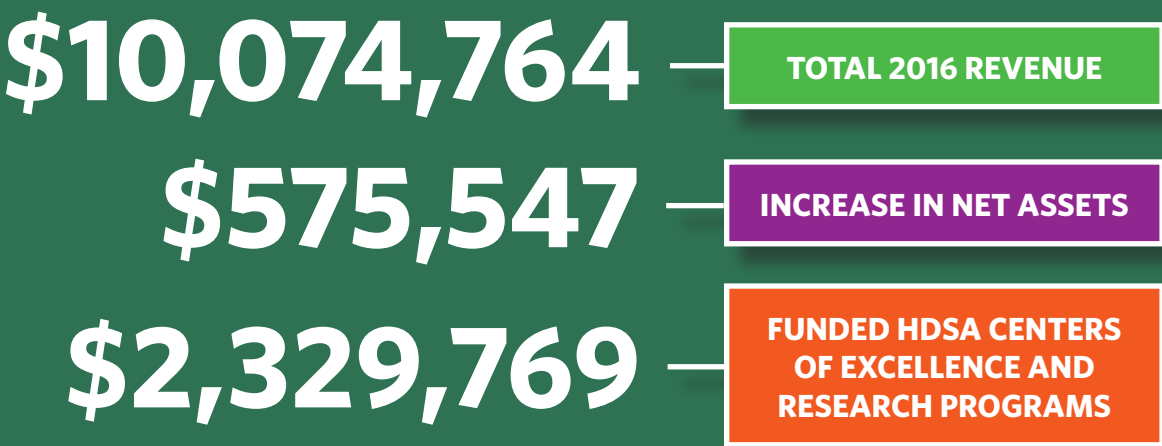
AS OF DECEMBER 31, 2016 AND 2015

	2016	2015
SUPPORT & REVENUE		
Public donations	2,245,579	2,813,604
Foundation grants and corporate contributions	1,749,617	1,946,618
Federal campaign	303,133	289,481
Investment income	13,170	7,615
Donated services and materials	301,028	539,033
Other	5,883	22,913
Total Support and Revenue	4,618,410	5,619,264
EXPENSES		
Program services:		
Research	1,959,619	1,727,027
Family services	2,275,034	1,949,944
Education	1,540,144	1,553,769
Chapter development	1,004,040	1,014,896
	6,778,837	6,245,636
Supporting services:		
Management and general	1,060,855	913,562
Fundraising	1,095,412	1,148,113
	2,156,267	2,061,675
Total Expenses	8,935,104	8,307,311
Change in net assets before non-operating income	(4,316,694)	(2,688,047)
Non-operating income:		
Special events:		
Gross receipts	5,456,354	4,628,905
Less: direct costs	(564,113)	(598,394)
Net income from special events	4,892,241	4,030,511
Increase in Net Assets	575,547	1,342,464
Net assets - beginning of year	5,149,828	3,807,364
Net Assets - December 31	5,725,375	5,149,828

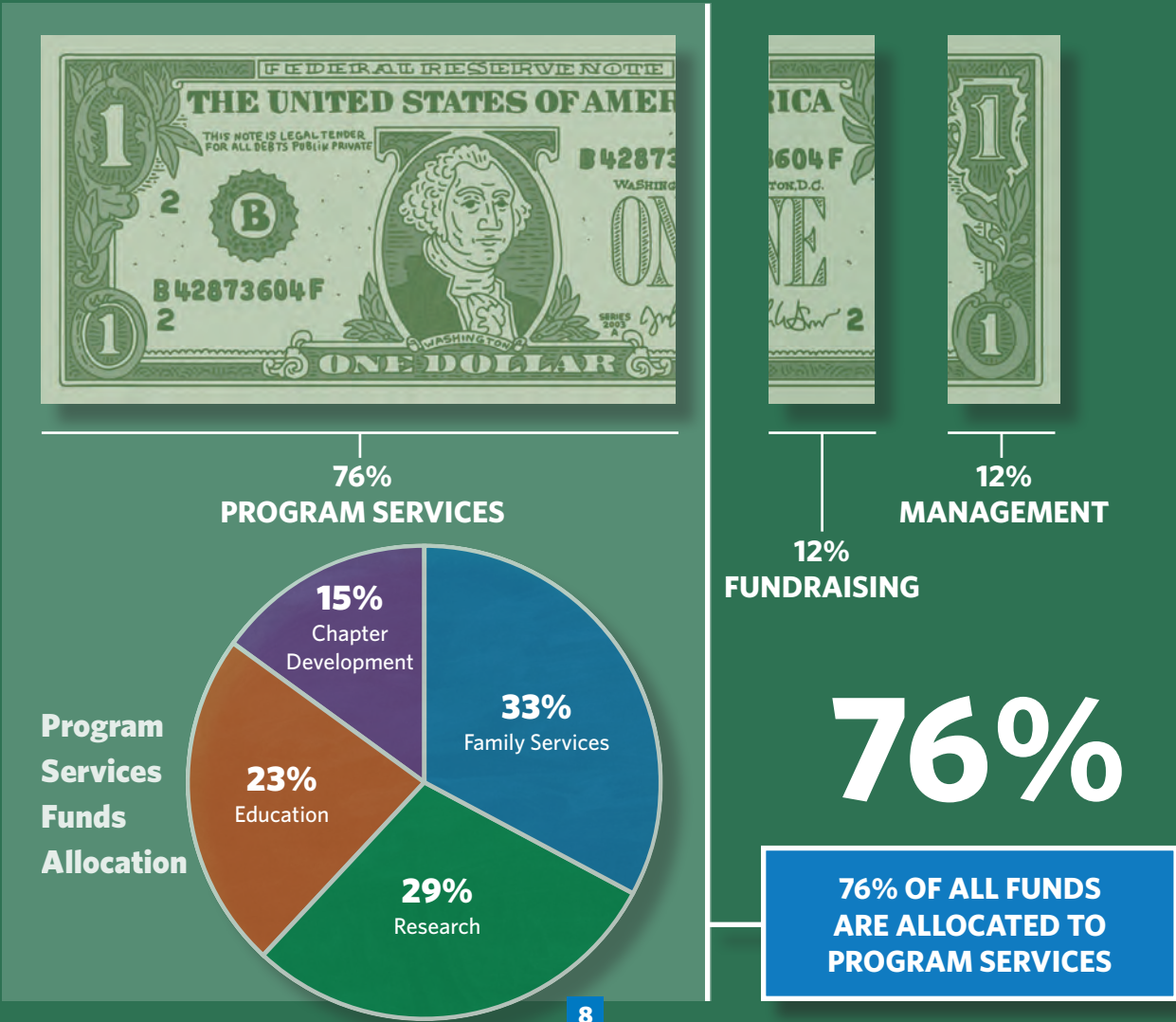
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For more information about Planned Giving at HDSA, please contact Assistant Director of Major and Individual Giving Jon Hogan at 212.242.1968 ext. 232 or jhogan@hdsa.org.



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Our Mission:

To improve the lives of people with Huntington's disease and their families.

Our Vision:

A world free of Huntington's disease.





Help for Today, Hope for Tomorrow.



2016 Annual Report

**HUNTINGTON'S DISEASE
SOCIETY OF AMERICA**

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