



Huntington's Disease
Society of America

2017 ANNUAL REPORT



50 YEARS OF SERVICE
1967-2017



HDSA Founder, Marjorie Guthrie



LOOKING BACK. MOVING FORWARD.

2017 gave us the opportunity to reflect on 50 years of service to the Huntington's disease community while we worked tirelessly to continue Marjorie Guthrie's epic crusade to educate people around the globe about HD and hopefully one day rid the world of this devastating disease.

In 1967, Marjorie Guthrie set out to "do something" about Huntington's disease — the same disease that took her husband Woody and threatened their children. Fifty years later, HDSA has continued to educate families, physicians, researchers, politicians and reach many more about the impact that HD has on families.

Today, HDSA provides more cost-effective resources to families and supports more meaningful research initiatives than ever before. Thanks

to our extraordinary volunteers who lead the Society and make up HDSA's Chapters & Affiliates, HDSA generated unprecedented awareness and funds to support our mission to improve the lives of people with Huntington's disease and their families.

Fifty years has armed us with the experience needed to fight HD. Until HD has been defeated, our fight will not stop.

Sincerely,



Arik Johnson

Dr. Arik Johnson
Chairman of the Board of Trustees



Louise Vetter

Louise Vetter
President & CEO



President Jimmy Carter
congratulating
Marjorie Guthrie.

50 YEARS OF SERVICE

In 1967 Marjorie Guthrie founded the **Committee to Combat Huntington's Disease** (now known as the **Huntington's Disease Society of America**). When her husband Woody Guthrie died from HD at age 55, Marjorie began her epic crusade to educate the world about this devastating brain disorder. Today, HDSA continues to carry out Marjorie's vision to "do something" about HD through a comprehensive portfolio of advocacy, education, family services and research programs.



2017 HIGHLIGHTS

HDSA CENTERS OF EXCELLENCE

In 2017, HDSA increased its **Centers of Excellence** program to 41 facilities across the United States. The HDSA Centers of Excellence provide an elite multi-disciplinary approach to Huntington's disease care and research. For a complete listing of HDSA's Centers of Excellence please visit HDSA.org/COE



HD: HIDDEN NO MORE

As a lead partner in the **#HDdenmore** (pronounced *hidden no more*) project, HDSA played an integral role in organizing a memorable meeting with Pope Francis at the Vatican in May of 2017. HDdenmore led to unprecedented global awareness for Huntington's disease where Pope Francis addressed HD families: "May none of you ever feel you are alone. May none of you feel you are a burden. May no one feel the need to run away."



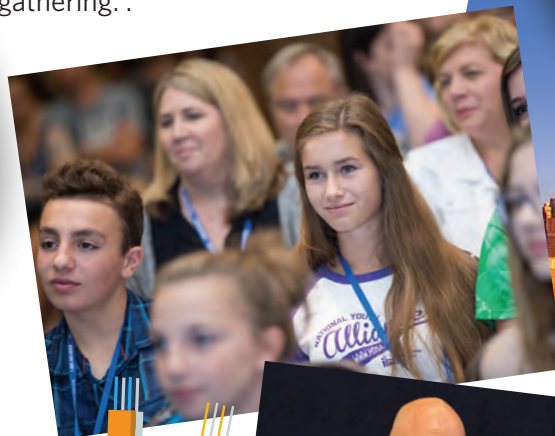
N.Y.C. MARATHON

HDSA's New York City Marathon team, made up of twenty-seven runners from thirteen states, raised more than \$168,000 in 2017 ranking 12th among the 350+ charity partners who participated in the largest marathon in the world.



HDSA CONVENTION

HDSA held its **32nd Annual Convention** in Schaumburg, Illinois on June 22-24, 2017. The HDSA Convention is the world's largest Huntington's disease family gathering. .



- 978 ATTENDEES
- 185 SCHOLARSHIPS GRANTED
- 91 NYA MEMBERS
- 47% FIRST-TIME ATTENDEES
- 36 EXHIBITORS



NYA

In 2017, **HDSA's National Youth Alliance (NYA)** continued to expand its youth programs and resources to assist children and young adults in their HD journey. With retreats and support groups available across the country, youth impacted by HD have more resources than ever before. For more info about HDSA's National Youth Alliance please visit HDSA.org/NYA.



TEAM HOPE

HDSA's Team Hope Walk Program is the organization's signature grassroots fundraising campaign designed to provide hope and support for those touched by this devastating disease.



- TOTAL FUNDS: \$2.3 MILLION
- 105 TEAM HOPE WALKS
- 14,000+ WALKERS





HDSA'S HD ADVOCACY

Although 2017 was complex with a shift in administration, it did not deter HDSA's effort to have an impact on Capitol Hill as HDSA reintroduced the **HD Parity Act (HR 2589/S1197)** in the House & Senate. For more information about HDSA's advocacy efforts please visit HDSA.org/takeaction.

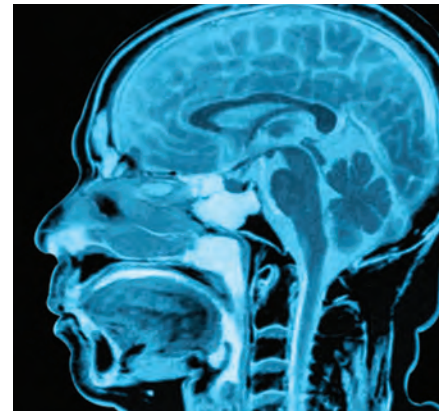
HDSA RESEARCH

HDSA continues to be a world-leader in HD research and communication. In 2017 HDSA funded nearly \$1 million towards meaningful HD research programs such as:

- **The Berman-Topper Family HD Career Development Fellowship**
- **HD Human Biology Project**
- **Donald A. King Summer Research Fellowship**



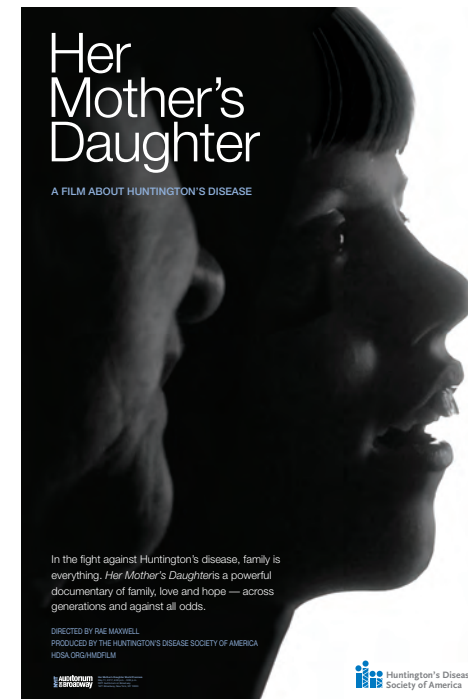
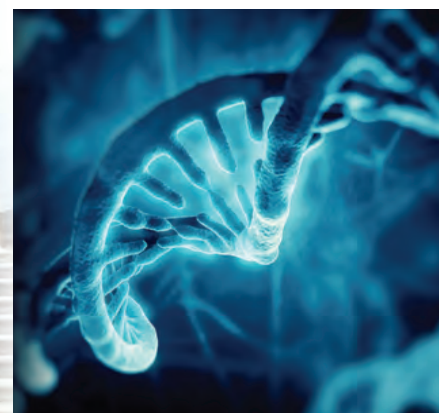
Pictured above; the 2017 Berman-Topper Family HD Career Development Fellowship recipients Dr. Tamara Maiuri, McMaster University (left) and Dr. Sarah Hernandez, University of California at Irvine.



HDSA also helped form the **HD-Coalition Patient Engagement (HD-COPE)** — a global partnership with the Huntington Society of Canada and the European Huntington Association to add valuable patient representative input to clinical trials.



To continue connecting families with appropriate clinical trials, HDSA collaborates with its partners in HD education to increase the utilization of HDSA's **HD TrialFinder**. For more information about clinical trials and to enroll visit HDTrialFinder.org.



HER MOTHER'S DAUGHTER

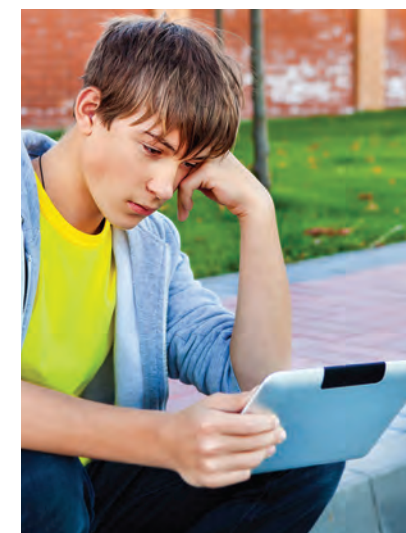
In 2017, HDSA produced the powerful documentary **Her Mother's Daughter** to raise awareness of Huntington's disease. Directed by **Rae Maxwell**, *Her Mother's Daughter* captures the impact the HD and Juvenile HD has had on the O'Donnell family. To view *Her Mother's Daughter* for free visit HDSA.org/HMDFilm.



HDSA DIGITAL SUPPORT

HDSA goes digital — *and free* — with world-class resources for the HD community. In 2017, HDSA's online resources expanded so families could get the support they needed from the comfort of their home by visiting the following sites:

- **Online Support Groups:**
HDSA.org/OSG



- **Telehealth:**
HDSA.org/telehealth



- **Free HD Navigator App:**
iTunes store or Google Play.



FINANCIALS

STATEMENTS OF FINANCIAL POSITION

AS OF DECEMBER 31, 2017 AND 2016

	2017	2016
ASSETS		
Cash and cash equivalents	\$ 6,755,658	5,682,692
Investments	476,225	496,158
Pledges and contributions receivable, net	1,639,252	905,233
Prepaid expenses and deposits	161,151	146,030
Property and equipment, net	53,060	50,747
Total Assets	9,085,346	7,280,860
LIABILITIES		
Accounts payable and accrued expenses	116,013	120,396
Accrued compensation	270,255	257,019
Grants payable	1,415,064	1,032,367
Event revenue received in advance	87,457	31,254
Deferred rent obligation	108,034	93,118
Obligation under capital lease	17,499	21,331
Total Liabilities	2,014,322	1,555,485
NET ASSETS		
Unrestricted		
Undesignated	991,626	1,047,304
Board-operating reserve	1,278,217	932,251
	2,269,843	1,979,555
Temporarily restricted	4,551,181	3,495,820
Permanently restricted	250,000	250,000
Total Net Assets	7,071,024	5,725,375
Total Liabilities And Net Assets	9,085,346	7,280,860

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

YEAR ENDED DECEMBER 31, 2017
(With summarized financial information for 2016)

	2017	2016
SUPPORT & REVENUE		
Public donations	3,071,181	2,245,579
Foundation grants and corporate contributions	2,941,556	1,749,617
Federal campaign	359,352	303,133
Investment income	15,472	13,170
Donated services and materials	278,979	301,028
Other	79,833	5,883
Total Support and Revenue	6,746,373	4,618,410
EXPENSES		
Program services:		
Research	1,738,768	1,959,619
Family services	2,762,400	2,275,034
Education	1,670,796	1,540,144
Chapter development	1,000,281	1,004,040
	7,172,245	6,778,837
Supporting services:		
Management and general	1,107,145	1,060,855
Fundraising	1,187,521	1,095,412
	2,294,666	2,156,267
Total Expenses	9,466,911	8,935,104
Change in net assets before non-operating income	(2,720,538)	(4,316,694)
Non-operating income:		
Special events:		
Gross receipts	4,628,736	5,456,354
Less: direct costs	(562,549)	(564,113)
Net income from special events	4,066,187	4,892,241
Increase in Net Assets	1,345,649	575,547
Net assets - beginning of year	5,725,375	5,149,828
Net Assets - December 31	7,071,024	5,725,375

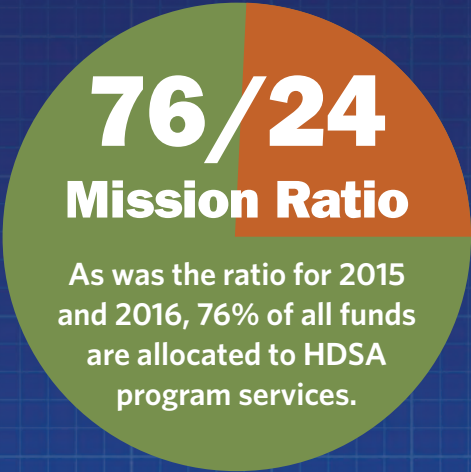
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YOUR HDSA DOLLARS AT WORK

BASED ON AUDITED FINANCIALS FOR FISCAL YEAR ENDED DECEMBER 31, 2017

OVERVIEW

- Total 2017 revenues of \$10.8 million
- Exceeded budget by \$1 million
- Funded \$2.1M in new grants

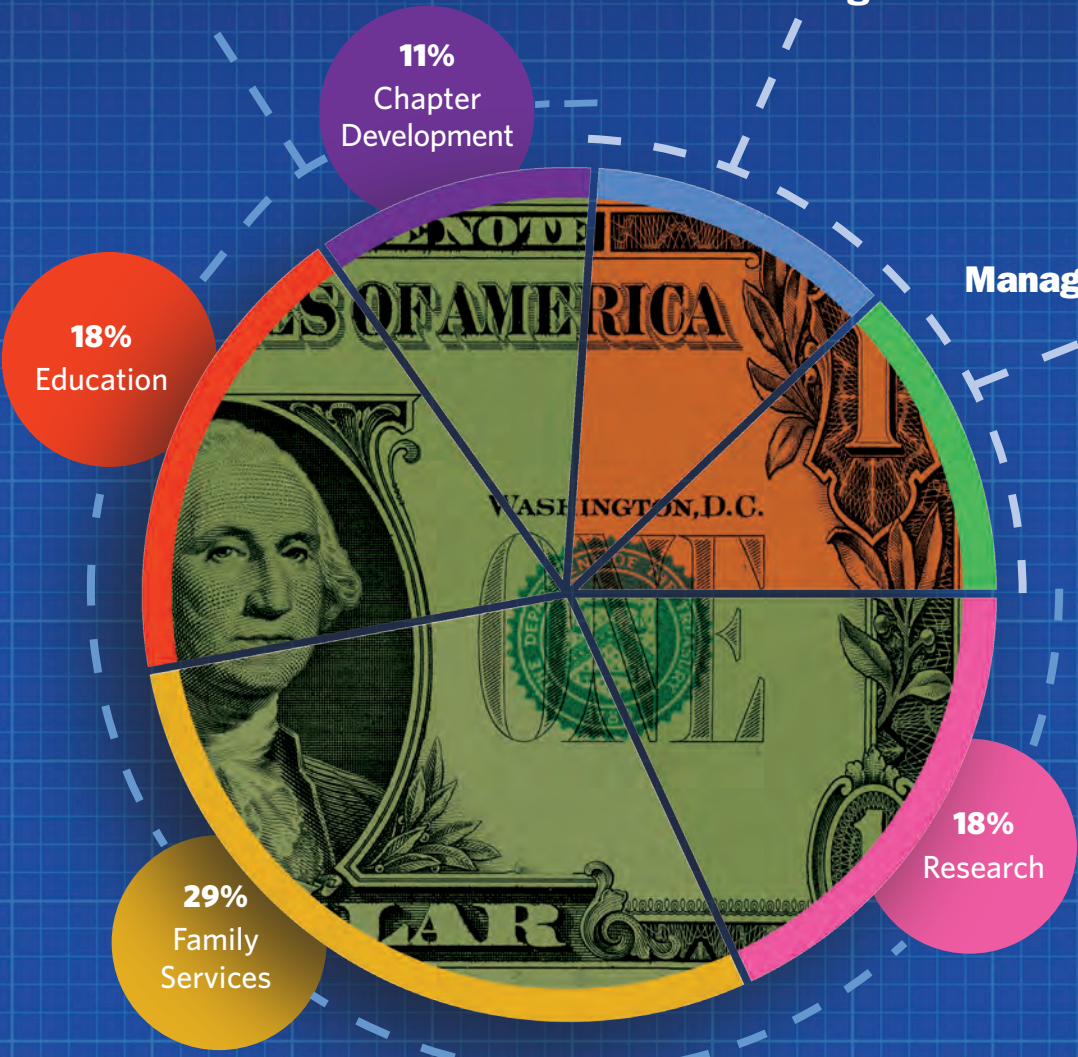


FUNDS ALLOCATION

Program Services: 76%

Fundraising: 12%

Management: 12%



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**Huntington's Disease
Society of America**

HDSA MISSION STATEMENT

*To improve the lives of people affected by
Huntington's disease and their families*

HDSA VISION

A world free of Huntington's disease.

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THANK YOU TO OUR DONORS FOR THEIR GENEROUS SUPPORT OF \$1,000 OR MORE.

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Until the day when scientists find a cure for HD, families across the country require access to the crucial research, care, and advocacy programs that HDSA provides. Our Planned Giving program ensures that as we look to the future we'll have the resources we need to continue providing help and hope to the HD community. By including HDSA in your estate plans as the beneficiary of insurance, stock, real estate, or retirement plan, you can create a legacy of giving that guarantees future generations will have the vital support they'll need to confront this devastating illness. With the help of a financial planner, you can arrange your gift in a way that ensures the largest possible sum will have the strongest possible impact on the lives of those affected by HD in the decades to come.

Join us in thanking the following individuals who've committed to support HDSA through their Wills and Estate Plans:

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For more information about HDSA's Planned Giving program, please contact Jamison Skala, Director of Development, at (212) 242-1968 ext. 235 or jskala@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.

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