



## 2018 ANNUAL REPORT



E.J. Garner



Louise A. Vetter

## GREETINGS

Dear Friends,

2018 was an opportunity for us to reflect on 50 years of service to the Huntington's disease community and look ahead to continuing our mission to improve the lives of everyone with HD and their families. Thanks to exciting advancements in HD research we have more resources and hope than ever before. No longer are we wondering "if" we can defeat HD; now it's just a matter of "when"! How did we get here? Well, it's pretty simple... The answer is you! Whether you attended an HDSA event, participated in an awareness campaign, or made a gift online, your contribution directly supported HDSA's research, education and advocacy programs. Perhaps you joined the ENROLL-HD study, participated in a clinical trial or completed surveys that played an integral role in providing researchers with valuable information? Your direct involvement in clinical science is helping doctors and scientists with insights that are improving care today. Maybe you helped one of HDSA's incredible Chapters and Affiliates around the country serve and support HD families? The volunteer leadership of HD families nationwide is what brings HDSA's mission to life - raising awareness of HD, educating communities about the needs of our families and providing direct assistance through our extensive network of support groups, social workers and HDSA Centers of Excellence.

Because of you, we are helping more families than ever before and laying a path to a healthier tomorrow.

**On behalf of the entire HD community, thank you!**

Where do we go from here? Luckily, that's another simple answer... we keep moving forward. There's a lot of work to be done in order to help every family affected by Huntington's disease. We must continue to grow in numbers and continue to provide more resources to HD families in need. We are so grateful for the amazing dedication and support of the HD community and our partners in this fight. We look forward to providing more help and hope in 2019, and to seeing you at HDSA events across the country.

**E.J. Garner**  
*Chair, National Board of Trustees*

**Louise A. Vetter**  
*President and Chief Executive Officer*





# 2018 HIGHLIGHTS

## HDSA CENTERS OF EXCELLENCE

The 2018 HDSA Centers of Excellence program expanded to 43 Centers from 41 in 2017. Since 2015 the program has grown from just 20 — a 115 percent increase in four years! The HDSA Centers of Excellence are multi-disciplinary care teams with expertise in Huntington's disease that share an exemplary commitment to bringing comprehensive care and making clinical science possible. **For more info about HDSA's Centers of Excellence Program please visit [www.HDSA.org/coe](http://www.HDSA.org/coe).**



## 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.

## ENROLL-HD REACHES 20,000 PARTICIPANTS WORLDWIDE!

Enroll-HD's 20,000<sup>th</sup> participant was recruited at the study site in Leuven, Belgium. This extraordinary milestone was made possible thanks to the efforts of the sites and the families. For more info about Enroll-HD please visit [www.enroll-hd.org](http://www.enroll-hd.org).



Jennifer Simpson (left) interviews NYA's Mary Ann Emerick.

## HERE'S THE DEAL

HDSA's *Here's the Deal* is a new series on HDSA's YouTube channel that tackles important topics to help you navigate through your journey with Huntington's disease. Hosted by HDSA's **Jennifer Simpson, LCSW**, *Here's The Deal* provides incredible insight into subjects such as suicide, survivor's guilt, relationships and much more.

## NFL SUPERSTAR AARON DONALD SUPPORTS HDSA

The NFL campaign **#MyCauseMyCleats** gives players the opportunity to support their favorite charities by wearing custom cleats. **Aaron Donald** from the **L.A. Rams** wore cleats featuring the HDSA logo to support families affected by Huntington's disease.







At left: Caralyn Duke  
with top fundraiser  
Maggie Kiselick

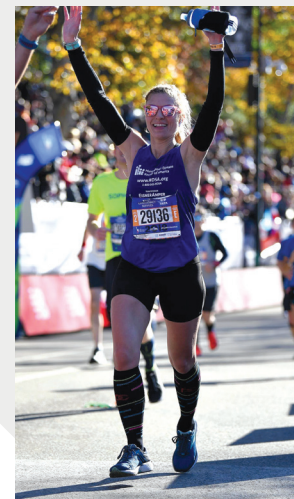
Bellow: Ally Bejma

## HDSA'S NEW YORK CITY MARATHON TEAM

Twenty-five runners from across the United States ran the **2018 TCS New York City Marathon** to support the Huntington's Disease Society of America. HDSA's Marathon Team raised nearly \$120,000 to support HDSA's mission. The top fundraiser for 2018 was **Maggie Kiselick** from New York City who raised more than \$10,000! Thank you to all our runners, supporters and to **EisnerAmper** for sponsoring **HDSA's Charity Cheer Zone**.

### 2018 HDSA NYC Marathon Team Roster:

*Samantha Alexander, Ray Baldwin, Ally Bejma, Arthur Bergoeffen, Jonathan Bolick, Julie Chagnon, Peter DeVore, Caralyn Duke, Derrick Flanders, Brad Golden, Rhonda Hannahane, Raegan Heitzenrater, Marianna Jamadi, Philip Kiselick, Maggie Kiselick, M.C. Kiselick, Brenda Lager, Carmen McDowell, Brendan Milnamow, Katharine Moser, Renee Moser, Daniel Pirrello, Amanda Polli, Mallory Temple and Jessica Wickers.*



## MAY IS HD AWARENESS MONTH, SO #LETSTALKABOUTHD!

Each May the Huntington's Disease Society of America turns up the global volume on HD awareness by getting little help from our celebrity friends. From musicians and actors to athletes and journalists, new folks take part in the **#LetsTalkAboutHD** video campaign to educate more people about Huntington's disease. With the power of social media, HDSA has been able to generate more HD awareness than ever before!

HDSA kicked off **HD Awareness Month** with **Night of the Machine** — a concert at Le Poisson Rouge in New York City featuring **Brendan Fletcher, Dave Hause** and **Martha Wainwright** to pay tribute to the organization's music heritage. Martha was joined on stage by her father, **Loudon Wainwright III**.



*Brendan Fletcher, Dave Hause, and Loudon Wainwright III with daughter Martha.*

# NIGHT OF THE MACHINE

CONCERT TO BENEFIT  
THE HUNTINGTON'S  
DISEASE SOCIETY  
OF AMERICA

THURSDAY, MAY 10 2018  
(LE) POISSON ROUGE  
MAIN SPACE  
DOORS: 6:00 PM  
SHOWTIME: 7:00 PM

Celebrating 50 years of the Guthrie Family Legacy in the fight against Huntington's disease. All proceeds benefit the Huntington's Disease Society of America.

**FEATURING**  
**MARTHA WAINWRIGHT**

**DAVE HAUSE**

**BRENDAN FLETCHER**  
AND OTHER SPECIAL GUESTS

**50**  
50 YEARS OF SERVICE  
1967-2017  
[www.hdsa.org](http://www.hdsa.org)

(le) poisson rouge

158 Bleeker Street  
New York, NY 10012  
[www.lpr.com](http://www.lpr.com)  
#LiveatLPR

f t i



## FREEZE HD EVENT RAISES NEARLY \$200,000

On September 22, 2018 more than 300 guests attended the **Fourth Annual Freeze HD** event in Los Angeles that raised nearly \$200,000! The event was held at Neuehouse in Hollywood and honored long-time supporter and HD family member **Kipenzi Chidinma**. The evening included an incredible auction, delicious food and live entertainment. Celebrities such as **Scott Porter, Jason Ritter, Tyler Ritter, Caitlin Carver, Kate Miner, Angelique Cabral, Jeff Meacham** and many more were on-hand to generate much-needed funds and awareness for the HDSA family.



Above: Tyler Ritter,  
Scott Porter, Louise Vetter,  
Kipenzi Chidinma and  
Jason Ritter

At Right:  
Jenne Coler-Dark,  
Kate Miner and  
Becky Johnson



## INSIDE THE O'BRIENS COMING TO THE BIG SCREEN

Director **Brett Haley** and co-writer **Marc Basch** have been working with the Huntington's Disease Society of America to meet with HD families in order to prepare for the film adaption of best-selling author **Lisa Genova's** novel **Inside The O'Briens** — a story of a Boston family's struggle with HD.



Marc Basch  
& Brett Haley

## THIS WEEK IN HD RESEARCH

In 2018 HDSA launched **This Week In HD Research**. This weekly blog is curated by HDSA's **Dr. Leora Fox** who provides updates on HD science and meaningful news from around the neuroscience world. To read the latest post visit **HDSA.org/blog**.



Dr. Leora Fox





1,046  
TOTAL  
ATTENDEES

## HDSA'S 33<sup>RD</sup> ANNUAL CONVENTION

The Huntington's Disease Society of America hosted its 33rd Annual Convention from June 7th-9th at the Los Angeles Marriott in California. With 1,046 attendees, this was the largest Convention in the 50-year history of the organization breaking the previous record of 1,001 in Minnesota back in 2011. The HDSA Convention is the world's largest conference for families affected by Huntington's disease.

52.3%  
WERE FIRST-TIME  
ATTENDEES

96  
N.Y.A. MEMBERS  
ATTENDED

52  
SCHOLARSHIPS  
WERE GRANTED

100  
EXHIBITORS  
PARTICIPATED



### Follow Us!

Stay connected with all the latest HD news and events by following HDSA on social media! HDSA's social media pages provide valuable content to keep you up to date on everything HD and HDSA.

Facebook: /HDSofA

Twitter: @HDSA

Instagram: HDSANational

YouTube: HDSA.org/youtube



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HDSA 2018 ANNUAL REPORT



# 2018 REPORTS

## HDSA RESEARCH

Hope shines brighter than ever that future generations may one day be free of Huntington's disease. It has shaped up to be a year unlike any other for the HD community. In 2018, HDSA commemorated 50 years of service to the HD community and also marked the 25th anniversary of the identification of the huntingtin gene. The year



**Genentech**

*A Member of the Roche Group*

culminated with the announcement from Roche/Genentech that the first ever Phase 3 clinical trial to test a huntingtin-lowering drug will begin in 2019 and will include sites in the United States.

HDSA continues to be a world leader in supporting HD research by funding research programs such as the HD Human Biology Project, Berman/Topper Family Career Development Fellowship and the Donald A. King Summer Fellowship.

## NATIONAL YOUTH ALLIANCE

2018 was a banner year for youth programs! In partnership with local HDSA Chapters and HDSA Centers of Excellence, we held four youth retreats across the country for National Youth Alliance (NYA) members to experience a week-end of community, education, laughter and healing. Sponsored by Teva, these retreats are at no cost to families, including travel and hotel stays for young people and their guardians.



The NYA also launched the Regional Lead Program. This program trained 21 young leaders to be resource hubs in their areas, available to be a peer support for young people,

connecting to the local social workers and Centers of Excellence as well as working with chapters and affiliates to bolster local support for young people.

We also launched our Youth Social Worker Pilot Program in 2018! With funding from the Griffin Foundation, HDSA on boarded and trained two social workers within the HDSA network, Jessica Marsolek and Katie Dykman, adding youth specific work to

their array of services provided to the HD community. This program hopes to build year over year to grow a network of youth social workers around the country, available to provide important supportive social work services to young people impacted by HD.





## SUPPORT SERVICES

HDSA is proud of the services that we provide to families throughout the country. Social workers in HDSA Centers of Excellence, chapters, regions and other HD clinics assist families in their 45 states and across their borders. Our professional training brought 60 HD social workers together prior to convention in Los Angeles. This in-person educational event helps HD social workers provide the best and up to date information on assisting HD families with their concerns.

HDSA also provides *free* online resources such as the HD Trialfinder, Telehealth and online support groups.

**Go to [HDSA.org](http://HDSA.org) to learn more about these valuable programs.**

## HD EDUCATION

2018 continued to be an outstanding year for HDSA's lay and professional educational efforts. In the area of lay education, HDSA was able to support 49 field based educational days which included guest speakers at support groups as well as full and half day programs. In addition to out-standing programming in the areas of both care and research, every attendee received an HDSA information packet that contained valuable materials about support groups, HDSA Centers of Excellence and chapters/affiliates in their region. More than 2,700 HD family members and healthcare



*Segment from the Module 1 online course, 'HD in the 21st Century' with Drs. Victor Sung and Erin Furr-Strimming.*

professionals attended these events with seven multi-track state conventions attracting more than 100 family members to each. HDSA thanks Teva for their generous unrestricted educational grant which made these events possible.

## ADVOCACY

With more than 30,000 e-advocates, 2018 was an active year for HD advocacy. Our community continued to focus our efforts on the HD Parity Act, working on gaining new co-sponsors while planting the seeds for work in 2019. We partnered with the National Organization of Rare Disorders (NORD), the American Brain Coalition and the National Health Council to fight against measures that would have

negatively impacted families with HD.

We fought against cuts to Medicare and Medicaid, roll-backs of protections for individuals with pre-existing conditions, the creation of high-risk pools which would have raised healthcare costs for folks with complex and chronic diseases like HD, and fought successfully for increases to the NIH budget for neurodegenerative disease research. HDSA focused on



joining forces with partners to amplify the voice of our community and join the bigger fight to improve and protect access to healthcare as well as expand resources for important research opportunities for HD families. Although gridlock dominated Washington D.C. in 2018, HDSA and HD advocates worked to make sure that we are still making progress towards improving the lives of individuals and families impacted by HD.



# FINANCIALS

## Statements of Financial Position

AS OF DECEMBER 31, 2018 AND 2017

	2018	2017
<b>ASSETS</b>		
Cash and cash equivalents	\$ 8,850,855	\$ 6,755,658
Investments	113,272	476,225
Pledges and contributions receivable, net	1,338,533	1,639,252
Prepaid expenses and deposits	152,770	161,151
Property and equipment, net	47,443	53,060
Website costs, net	8,181	
<b>Total Assets</b>	<b>10,511,054</b>	<b>9,085,346</b>
<b>LIABILITIES</b>		
Accounts payable and accrued expenses	116,344	116,013
Accrued compensation	185,723	270,255
Grants payable	1,447,523	1,415,064
Event revenue received in advance	14,578	87,457
Deferred rent obligation	116,711	108,034
Obligation under capital lease	13,250	17,499
<b>Total Liabilities</b>	<b>1,894,129</b>	<b>2,014,322</b>
<b>NET ASSETS</b>		
<b>Without donor restrictions</b>		
Undesignated	1,372,640	991,626
Board-operating reserve	1,518,483	1,278,217
	2,891,123	2,269,843
<b>With donor restrictions</b>		
Purpose restrictions	4,950,357	3,573,900
Time-restricted for future periods	525,445	977,281
Perpetual in nature	250,000	250,000
	5,725,802	4,801,181
<b>Total Net Assets</b>	<b>8,616,925</b>	<b>7,071,024</b>
<b>Total Liabilities And Net Assets</b>	<b>10,511,054</b>	<b>9,085,346</b>

**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, 2018

(With summarized financial information for 2017)

	2018	2017
<b>SUPPORT &amp; REVENUE</b>		
Public donations	3,654,204	3,071,181
Foundation grants and corporate contributions	2,337,869	2,941,556
Federated campaign	293,299	359,352
Special events (net of direct benefit to donors of \$681,911 and \$562,549 in 2018 and 2017, respectively)	4,332,708	4,066,187
Investment income, net	33,126	15,472
Donated services and materials	788,276	278,979
Other income	79,337	79,833
Total support and revenue before net assets released from restrictions	11,518,819	10,812,560
Net assets released from restrictions	0	0
<b>Total Support and Revenue</b>	<b>11,518,819</b>	<b>10,812,560</b>
<b>EXPENSES</b>		
<b>Program services:</b>		
Research	2,628,066	1,738,768
Family services	2,525,584	2,762,400
Education	1,605,661	1,670,796
Chapter development	1,033,072	1,000,281
	7,792,383	7,172,245
<b>Supporting services:</b>		
Management and general	954,268	1,107,145
Fundraising	1,226,267	1,187,521
	2,180,535	2,294,666
<b>Total Expenses</b>	<b>9,972,918</b>	<b>9,466,911</b>
Increase in net assets	1,545,901	1,345,649
Net assets - beginning of year	7,071,024	5,725,375
<b>Net Assets - End of Year</b>	<b>8,616,925</b>	<b>7,071,024</b>

**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.



# Your HDSA Dollars at Work

BASED ON AUDITED FINANCIALS FOR FISCAL YEAR ENDED DECEMBER 31, 2018

## OVERVIEW

- ▲ Total 2018 revenues of \$12.2 million.  
*Up from \$11.3 million in 2017.*
- ▲ Funded \$2.4 million in new grants.  
*HDSA Centers of Excellence and research grants.*



- ▲ Up from 76/24 which had been the ratio since 2015.

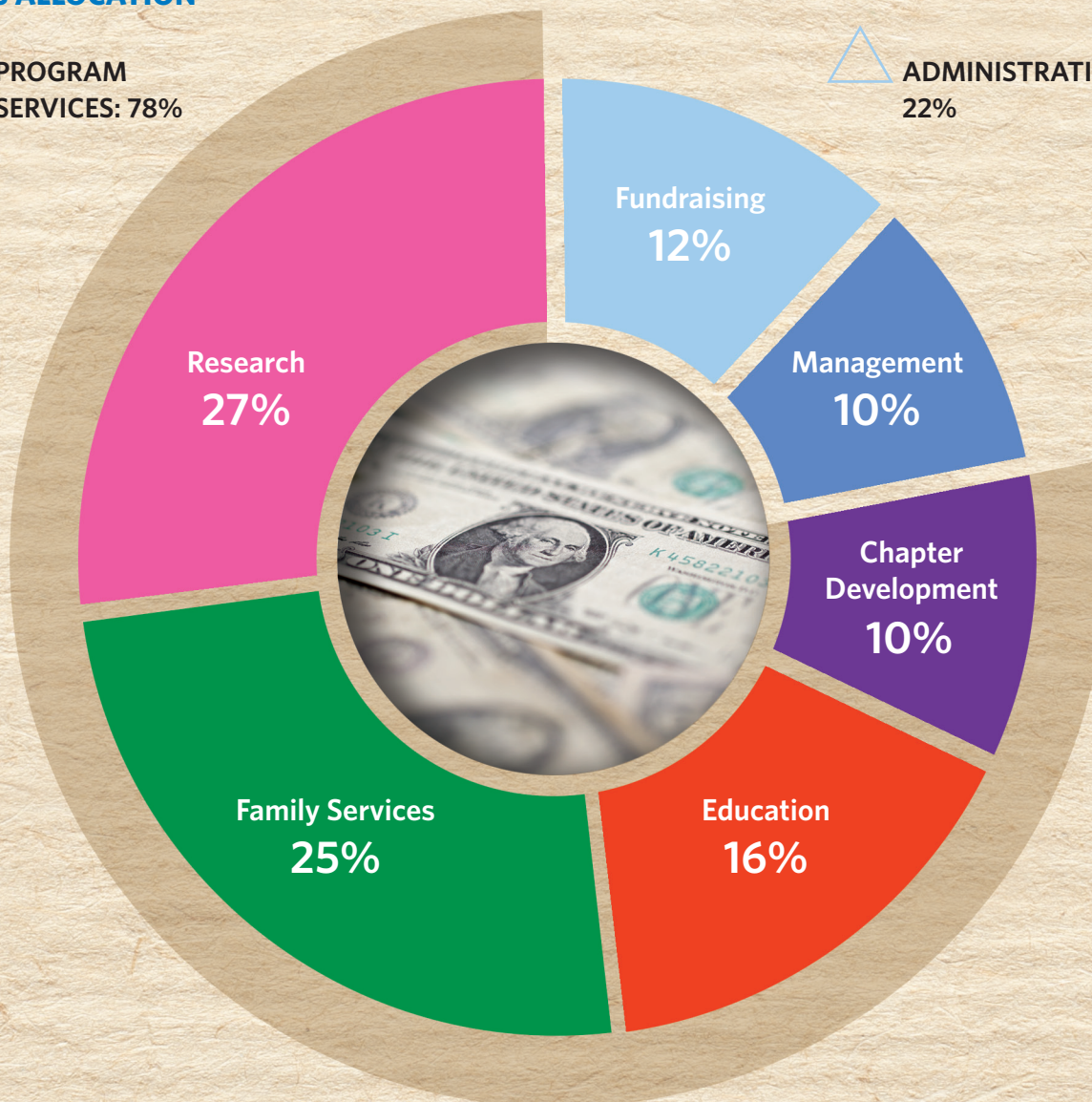
## FUNDS ALLOCATION



**PROGRAM  
SERVICES: 78%**



**ADMINISTRATION:  
22%**





## 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, education, and advocacy programs HDSA provides. The Marjorie Guthrie Society 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, real estate, appreciated securities, or retirement plan you can create a legacy of giving that guarantees future generations will have the vital support they need to confront this devastating illness. With the help of a financial planner, you can arrange your gift in a way that reduces your estate taxes and has 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 have committed to support HDSA through their estate plans:

*To learn more about the Marjorie Guthrie Society, or to inform us of your estate plans to support HDSA, please contact Jamison Skala, Director of National Development, at (212) 242-1968 ext. 235 or [jkskala@hdsa.org](mailto:jkskala@hdsa.org).*

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