



Huntington's Disease  
Society of America

**FIFTY YEARS OF SERVICE**  
**1967-2017**



**"She Came Along to Me"**

Woody Guthrie's love song to his wife and  
HDSA founder Marjorie Guthrie

# 2017 Year In Review



# A Tribute to Marjorie Guthrie

by Louise Vetter, HDSA's President & CEO

“Do you know what a hoper is? Well, that’s what your mama is, a hoper. She has more hopes per square inch than almost anybody else. Hopes about this and hopes about that, hopes about you, about me, about all of the relatives, hopes about lots of people, all people. I ought to say, she’s what’s called a planner. I guess she makes more plans in a day than fascism could tear down in a century. I really believe this was what made me like her... Every detail of her life is not only a plan, but it is a dream, and the whole plan of a better world is one that she dreams about always. And she dreams it so plain and so strong that everybody who gets close to her notices it, and picks it up like a radio taking music out of the air.”

**Woody Guthrie, about Marjorie Guthrie in a letter written to their unborn child**

It has been 50 years since Marjorie Guthrie “set out to do something” about Huntington’s disease, and the hopes and plans that she dreamt about in 1967 still resonate today at the Huntington’s Disease Society of America.

Her earliest vision of an organization of families united to provide help and hope to those affected by HD still guides HDSA. Its mission — to improve the lives of people affected by Huntington’s disease and their families — shapes every program and is a direct reflection of Marjorie’s dogged insistence that there be more care and unrelenting progress towards a cure.

Reflecting on Marjorie’s impact is as astounding as it is inspiring. At a time when communication was by mail and travel was limited, she armed herself with a typewriter, a suitcase and the needs of countless families on her shoulders. Powerfully and personally, she paved the way for a new brand of patient advocacy and integrated families into medicine and science like never before.

Marjorie created a community driven to create immediate change against a merciless foe. She envisioned, “There must be a strong, well-supported National organization to assure the widest possible distribution of all our educational materials to the HD families, doctors, neurologists... to the whole scientific community and health professionals everywhere.” With HDSA Chapters and Affiliates, social workers and support groups from coast to coast, HDSA has a truly national presence, so that families everywhere can connect to necessary resources.

Today, the HDSA Centers of Excellence program exemplifies Marjorie’s vision of a “team approach” to caring for HD families. At these world-class facilities located across the United States, families benefit from expert neurologists, psychiatrists, therapists, counselors and other professionals who have deep experience working with families and who work collaboratively to help families plan the best HD care program throughout the course of the disease.

Marjorie brought light to families hidden in the shadows, isolated by the shame and lack of understanding of the disease. By year’s end in 1967, Marjorie had a mailing list of 35 HD families and vowed that “we must

continue our search for HD families everywhere.” Today, HDSA engages more than 35,000 volunteers annually and reaches hundreds of thousands more through a vast network of national and international outreach and resources.

Today, the question HD families ask is not “if” there will be a treatment or cure, but “when”. Investing more than a million dollars annually to research programs like the HD Human Biology Project, Berman-Topper HD Career Development Fellowship and the Donald A. King Summer Research Fellowship, HDSA is fueling HD research that is patient-focused, solution-oriented and attracts new scientists to HD research.

Every member of the HDSA community is following in Marjorie’s footsteps. Like her, we travel to Capitol Hill to remove barriers to care for HD families. Like her, we gather clinicians and social workers to educate them about HD and connect their expertise to the families who depend on them. Like her, we inspire and invest in the scientific researchers who are deepening our understanding of HD and working to develop treatments. Like Marjorie, we gather with our families to support one another and dream together.

It is often said that the truest reflection of a life well lived is the family left behind. As we pause to recognize what would have been Marjorie Guthrie’s 100th birthday, the family that is today’s Huntington’s Disease Society of America is a tribute to her legacy. At HDSA, family is, and always has been, everything.

Clearly, our work is not done. Huntington’s disease has not yet been stopped. But because Marjorie Guthrie dreamed and planned and pushed forward to “do something” against the unrelenting foe of HD, we have one another — and we have hope.

Thank you.



*Louise Vetter is President and Chief Executive Officer of the Huntington’s Disease Society of America.*

# 2017 Highlights

## HDSA 50th Anniversary Kick Off Event

On October 25<sup>th</sup>, the Huntington's Disease Society of America collaborated with the Guthrie Family at The Triad Theater in New York City to pay tribute to the life and legacy of Marjorie Guthrie. This special night included inspiring presentations and incredible live music from **The Guthrie Family, Dr. Michael Hayden, Charlotte Landreau** from the **Martha Graham Dance**

**Company, Cole Quest, Noah Guthrie, Jackson Pines, Coyote & Crow** and **The Mammals**.

The event also celebrated the release of the 1968 & 1970 Woody Guthrie Tribute Concert Recordings. The Tribute concerts were the first major fundraisers for HDSA, and they featured **Bob Dylan, Joan Baez, Arlo Guthrie, Pete Seeger** and many more music legends.



Above: Anna Canoni, Nora Guthrie, Louise Vetter, and Nancy Wexler



Musical guests join together on stage for the evening's closing number — Woody Guthrie's classic, *This Land Is Your Land*.

## HDSA Center of Excellence Program Expands to 41 Sites Across the United States

The 2017 **HDSA Centers of Excellence** program expanded to 41 Centers from 39 last year, 29 in 2015 and 20 in 2014 — **a more than 100 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.

With the growth of the program, HDSA brings more "boots on the ground" to support HD affected families across the United States with care locations in 29 States plus the District of Columbia. In addition, three Centers have partner sites to expand care in Oregon, North Dakota and South Dakota.

HDSA awarded a total of \$1,159,750 to the Centers of Excellence program, an increase of \$67,750 from 2016.

"We are deeply committed to helping families with HD access experienced care," said Louise Vetter. "The expansion of the HDSA Center of Excellence program to more than 40 clinical care centers helps reduce the distance many families have to travel to find comprehensive HD services and increases access to the life-changing treatment and research opportunities that drive us forward towards finding a cure for this disease."



## Pope Francis' Special Audience with the Huntington's Disease Community

On May 18, HDSA served as an integral partner in a global coalition of Huntington's disease advocates that came together under the **HDdenmore** (pronounced 'Hidden No More') initiative to raise awareness of HD and mobilize action to end the stigma and shame around the disease that has persisted for generations. The leaders of this

effort were instrumental in bringing this issue to **Pope Francis**. The HDdenmore team includes **Charles Sabine, Elena Cattaneo, Ignacio Munoz-Sanjuan, Claudia Perandones, Louise Vetter** and many others!

For more information please visit [www. HDdenmore.com](http://www.HDdenmore.com)





#### HDSA's New York City Marathon Team Breaks Record in 2017

Twenty-seven runners from 13 states raised more than \$168,000 to support the fight against Huntington's disease at the 2017 New York City Marathon. Aside from conquering the 26.2 mile trek, this year's team became HDSA's highest fundraising marathon team ever and finished 12<sup>th</sup> among the 350+ charity partners! **TEAM HDSA's** highest fundraiser was **Doug Ballou**, raising more than \$26,000!

**TEAM HDSA's Roster:** Doug Ballou, Nicole Bordeau, Elizabeth Christian, Melody Coker,

Brian Cronk, James Del Carpio, Maryann Emerick, Arne Ericson, Heather Feragotti, Sydney Green, Dawn Guidone, Michelle Kehn, Lawrence Kosick, Nicole Ledesma, Karen Milek, Carl Moe, Lindsay Morrison, Ben Paul, Christopher Pfaff, Jason Reasor, Gail SchurLOW, Keli Scott-Ciota, Josh Silverstein, Miranda Spencer, Margaret Swartz, Guillermo Torres and Deborah Zimmermann.

**Thank you to everyone who ran and supported TEAM HDSA!**

#### Climb for the Cure

When the **Methot-Krepp family** of New York City decided to raise funds and awareness for Huntington's disease in honor of grandma Sandra who suffers from HD, 12-year-old **Kalev** suggested a family adventure in Tanzania — to climb Mount Kilimanjaro, the highest mountain in Africa. Their brave trek raised nearly \$20,000 to support the fight against HD, creating memories that will last a lifetime.



# Her Mother's Daughter

IN THE FIGHT AGAINST HUNTINGTON'S DISEASE, FAMILY IS EVERYTHING.

#### Her Mother's Daughter

The Huntington's Disease Society of America released the much-anticipated and powerful

documentary, ***Her Mother's Daughter***. The 48-minute film was directed by **Rae Maxwell** and produced by HDSA. *Her Mother's Daughter* introduces the world to **Kathi O'Donnell** and her granddaughter **Alyson**. The film shows the devastating impact that Huntington's disease (HD) & juvenile Huntington's disease (JHD) have had on the O'Donnell family.



**Filmmaker Rae Maxwell with Alyson**

"*Her Mother's Daughter* is a window into Kathi's inspiring journey as a caregiver as we see the different stages of HD & Juvenile Huntington's disease," said **Louise Vetter**. "The purpose of this film was to educate audiences about HD by telling one of the many inspiring stories from a brave family that battle this devastating brain disorder."

**To watch *Her Mother's Daughter* for free, please visit [HDSA.org/HMDfilm](https://HDSA.org/HMDfilm).**



## HDSA's Annual Convention

987

Attendees

185

Scholarships Granted

91

National Youth Alliance  
Members

47%

First-Time Convention  
Attendees

36

Exhibitors



**HDSA**  
32<sup>ND</sup> ANNUAL  
CONVENTION  
SCHAUMBURG, IL  
JUNE 22-24, 2017

With nearly 1,000 attendees, the Huntington's Disease Society of America hosted the second largest convention in 32 years!

Guests from around the globe came together in Schaumburg, Illinois on June 22-24 to take part in the world's largest Huntington's disease conference featuring HD families, clinicians, researchers and much more!

The Convention kicked-off with a **Team Hope** walk immediately followed by a fun sports-themed Welcome Reception on Thursday night. HD advocate and fitness professional **Shana Verstegen** delivered a wonderful keynote address on Friday morning. Later that day, the powerful new documentary, *Her Mother's Daughter*, was shown to a packed auditorium and received rave reviews.



**Shana Verstegen**  
with son Greyson  
at Convention

Saturday's schedule featured incredible research speakers from around the world including Italian senator and neurologist **Dr. Elena Cattaneo** and **Drs. Ed Wild** and **Jeff Carroll** from **HDBuzz**. The Convention concluded with Saturday night's gala which featured dinner, awards and entertainment.



### SAVE THE DATES!

The **33<sup>rd</sup> Annual HDSA Convention** will take place on **June 7-9, 2018** in **Los Angeles, CA.**

For more information about Convention, please visit us online at: [www.HDSA.org/Convention](http://www.HDSA.org/Convention).



## HDSA Convention Awards

**Woody Guthrie Advocacy Award**  
Connor Lind

**Woody Guthrie Advocacy Award**  
Jesse Lis

**HDSA Excellence In Care Award**  
University Of Alabama Birmingham  
HDSA Center of Excellence

**HDSA Marjorie Guthrie Award**  
Jamie Parish

**HDSA Youth Award**  
Maryann Emerick

**HDSA Youth Award**  
Melissa Ryant

**HDSA Juvenile HD Award**  
Alyson O'Donnell

**HDSA Research Award**  
Elena Cattaneo, Ph.D.

**HDSA Person of the Year**  
Christy Ericson

**Outstanding Family Service  
or Educational Program**  
Kentucky Chapter

**Outstanding Advocacy**  
Northeast Ohio Chapter

**Outstanding Fundraising Event**  
St. Louis Chapter

**Outstanding Board Development**  
South Dakota Chapter

**Affiliate of the Year**  
Tennessee Affiliate

**Chapter of the Year**  
South Dakota Chapter

**Best New Fundraising Event**  
Kentucky Chapter

**Outstanding Social Media Outreach**  
Illinois Chapter



# Region Highlights

Every year, HDSA's 50+ Chapters and Affiliates host more than 300 events across the country thanks to the amazing leadership of HD families and volunteers. Here are just a few!

## NORTHWEST REGION



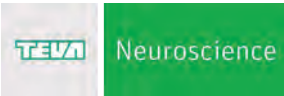
Seattle Team Hope Walk

**Seattle Team Hope Walk**  
Seattle, WA  
Washington State Chapter  
\$49,100

**Boise Team Hope Walk**  
Boise, ID  
Regional Event  
\$15,000

**Spokane Team Hope**  
Spokane, WA  
Washington State Chapter  
\$7,783

## SPECIAL THANKS TO OUR NATIONAL EVENT SPONSORS



**Teva Neuroscience**  
National Team Hope Sponsor and  
National Celebration of Hope Sponsor



**Asclepius Healthcare Resource**  
National Team Hope Sponsor

## PACIFIC SOUTHWEST REGION

**An Evening with Chris Berman —  
Celebration of Hope Gala**  
San Diego, CA  
San Diego Chapter  
\$350,500

**San Francisco  
Team Hope Walk**  
San Francisco, CA  
Regional Event  
\$84,400

**Shoot For A Cure**  
San Diego, CA  
San Diego Chapter  
\$65,800

## SOUTH CENTRAL REGION

**Denver “Heroes vs. Villains”  
Team Hope Walk and 5K Run**  
Denver, CO  
Rocky Mountain Chapter  
\$33,300

**North Texas Team Hope Walk**  
Frisco, TX  
Greater North Texas Affiliate  
\$26,900

**Central Houston Team Hope Walk  
and 5K Run**  
Houston, TX  
Houston Affiliate  
\$24,600

## UPPER MIDWEST REGION

**Minneapolis Team Hope Walk**  
Eden Prairie, MN  
Minnesota Chapter  
\$26,400

Minneapolis  
Team Hope Walk



**Be the Hope Reception**  
Saint Paul, MN  
Regional Event  
\$24,400

**Omaha Team Hope Walk**  
Omaha, Nebraska  
Omaha Affiliate  
\$22,400

## GREAT LAKES REGION



A Night in Venice

**A Night in Venice**  
Cleveland, OH  
Northeast Ohio Chapter  
\$191,500

**Illinois Team Hope Walk**  
Naperville, IL  
Illinois Chapter  
\$103,100

**Liberty Team Hope Walk**  
Liberty, MO  
Regional Walk  
\$90,000

## NEW YORK / NEW JERSEY REGION

**New York City Team Hope Walk**  
New York, NY  
Greater New York City Chapter  
\$113,000

**Corks & Forks Celebration of Hope**  
Albany, NY  
Albany, NY Chapter  
\$77,100

**Northern New Jersey Team Hope Walk**  
Edison, NJ  
New Jersey Chapter  
\$57,700

## MID-ATLANTIC REGION

**D.C. Metro Golden Gala**  
Chevy Chase, MD  
D.C. Metro Chapter  
\$98,300

**Maryland Crab Feast**  
Howard County Maryland  
Central Maryland Affiliate  
\$27,400

**Maryland Team Hope Walk**  
Baltimore Maryland  
Central Maryland Affiliate  
\$25,000



D.C. Metro Golden Gala

New York City Team Hope Walk



## NEW ENGLAND REGION

**New England  
Celebration of Hope Gala**  
Danvers, MA  
Regional Event  
\$51,600

**Boston Team Hope Walk**  
Boston, MA  
Massachusetts Chapter  
\$36,100

**New Hampshire Team Hope Walk**  
Durham, NH  
New Hampshire Affiliate  
\$18,300



New England  
Celebration of Hope Gala

## SOUTHEAST REGION

**26<sup>th</sup> Annual HD Triathlon**  
Miami, FL  
South Florida Chapter  
\$71,200

**Kevin Butler  
“Golf for a Cure”  
Tournament**  
Woodstock, GA  
Georgia Chapter  
\$30,500

**Georgia  
Team Hope Walk**  
Decatur, GA  
Georgia Chapter  
\$34,300



26<sup>th</sup> Annual  
HD Triathlon



Denver  
“Heroes vs. Villains”  
Team Hope Walk  
and 5K Run

Third Annual Freeze  
HD event held in  
Laguna Beach, CA  
raised more than  
\$142,000.

# Raising Awareness

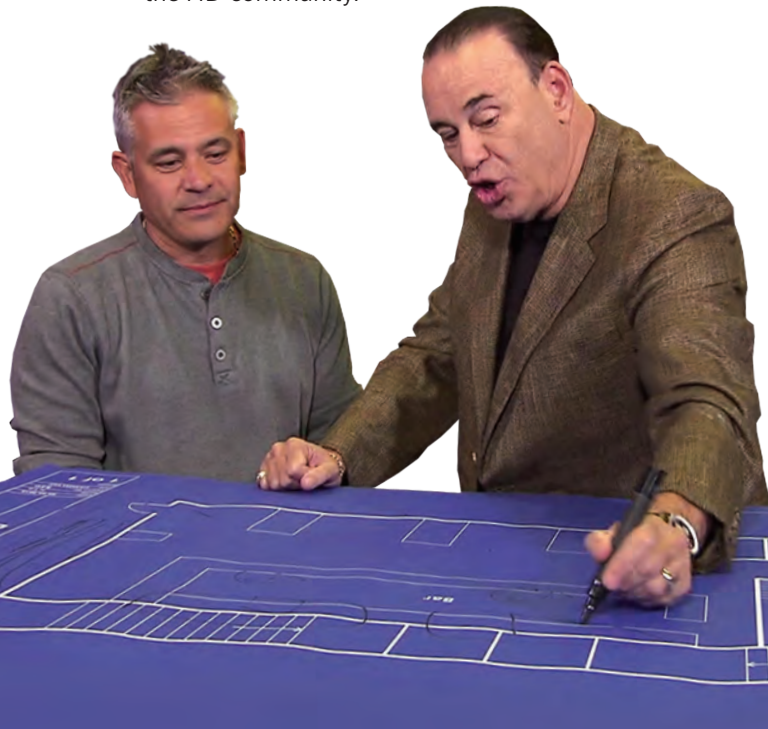


## HDSA Featured on Spike TV's Hit Show *Bar Rescue*

Host **Jon Taffer** went to Chicago, Illinois to try to rescue **Casual Tap**. The Casual Tap is owned by **Steve Magana** who is a full-time Chicago fire fighter. Steve's ex-wife is battling Huntington's disease.

To make matters worse, Steve's daughter has a 50% risk of inheriting HD. Jon and his crew decided to redesign

and reopen the Casual Tap featuring a new signature drink benefitting HDSA. Jon also made a personal donation to support our programs and services to the HD community.



## #LetsTalkAboutHD Continues to Provide Platform During HD Awareness Month

After the huge turnout of celebrity support in 2016, HDSA once again launched the **#LetsTalkAboutHD** social media campaign during HD Awareness Month in May. With many of 2016's celebrity videos still getting great attention such as **Mario Lopez, Scott Porter, Drew Brees**, the **Los Angeles Angels** and others, this year HDSA received support from Emmy Award winning actress **Tamara Braun**, star of the *Fast & Furious* films **Sung Kang**, sportscaster **Kenny Albert** and many more! However the greatest impact was made in the world of professional



soccer, where referees in partnership with the **Professional Referee Organization (PRO) / Professional Soccer Referees Association (PSRA)** wore blue wrist sweatbands to support former referee **Terry Vaughan**

who is battling HD. Throughout the month in every **Major League Soccer (MLS)** stadium, referees donned blue wristbands and Huntington's disease PSAs played for all to hear to encourage fans to join the fight against HD!

## HD Blue Hose Challenge

Started in August by HDSA Orange County Chapter's **Kaytrin Orel**, the **HD Blue Hose Challenge** became a huge hit across the country as HD supporters accepted the challenge to put on blue clothes and get sprayed with a hose!

HDSA's Omaha Affiliate accepted the #HDBLueHoseChallenge at their **18<sup>th</sup> Annual Team Hope Walk**. Partnering with the **Omaha Fire Department**, the HDSA Omaha Affiliate had a record-setting 120 walkers take the challenge!

## The Guthrie Sessions at HDSA

Although Woody Guthrie died from HD complications in 1967, HDSA has stayed true to its music roots to encourage hope. In its second season, **The Guthrie Sessions at HDSA** continued to attract incredible talent to help build HD awareness on social platforms. This year's performances included stars from the hit competition **The Voice** such as **Nick Howard, Brendan Fletcher** and **Ryan Quinn** as well as **Miner, Lizzie No, Bryan Hansen, GENTRY, Kate Faust, Jodi Valentine, Solomon Dorsey** and **Blake Morgan**.

The Guthrie Sessions Live event held on May 4<sup>th</sup> at the **Tenement Museum** in New York City also featured a very special rendition of *This Land Is Your Land* led by Woody and Marjorie Guthrie's daughter, **Nora**.



# Supporting HD Families

## Online Support Groups

In 2017, HDSA introduced free online support groups specifically for caregivers, those at-risk and young people ages 18-25. HDSA realizes that many people do not have access to an in-person support group because of distance, time constraints or difficulty with travel, so now families can join one of HDSA's licensed social workers for an hour-long support group to get much-needed information and valuable resources.

Groups are open to those around the country and the members will change with each group. Members must have access to phone and/or computer (audio and video needed) to participate.

**For more information about HDSA's Support Groups please email Anne Leserman, LCSW at [aleserman@HDSA.org](mailto:aleserman@HDSA.org) or visit [www.supportgroupscentral.com/hdsa](http://www.supportgroupscentral.com/hdsa).**



## HDSA's Free HDNavigator App

The Huntington's Disease Society of America launched their new mobile app, **HDNavigator**, featuring a collection of useful tools and resources for all members of the Huntington's disease community — patients, caregivers, at-risk individuals, as well as family members and friends. The app was made possible by a generous gift from Lundbeck Pharmaceuticals and is available for free download by searching "HDNavigator" or "HDSA" in iTunes or Google Play.

HDNavigator by HDSA is a first-of-its-kind personal assistant tool for individuals managing HD care. It features:

- Vital information for emergencies, including talking points and emergency contacts
- Medication and general life reminders, perfect for both patients and caregivers
- Contacts and notes sections for organizing information from appointments
- Communication boards to provide visual aids to help those who have trouble speaking
- A peer connector to find nearby HDSA Chapter members or National Youth Alliance members
- A mobile "locate resources" feature to find your closest HDSA Center of Excellence, Social Worker, Support Group or other resources

- An up-to-date event finder to help get involved in your community and meet others to make a difference
- A listing of important related links and suggested apps and games for HD information and brain health

"Managing a chronic, degenerative disease like Huntington's requires organizational skills, good communication and the ability to connect with valuable resources — all areas of function that are all affected in HD," said **Louise Vetter**. "HDNavigator is a simple, HD-specific tool that can help everyone in HD families have more access to support and personalized care information right in the palm of their hand."



### HDSA Launches Free Telehealth Support

In June, HDSA launched a new technology partnership with leading telehealth company **American Well®** to offer free online therapy to people affected by Huntington's disease. HDSA-trained licensed social workers and psychologists will be available on American Well's telehealth platform to help families in all 50 states to help manage the emotional symptoms and burden of HD. Funding for this program is provided by a generous grant from **Teva Pharmaceuticals**.

Psychiatric and behavioral problems are highly prevalent in families affected by Huntington's disease. Best estimates from mental health professionals indicate that approximately 50 percent of patients seen at HD clinics, such as HDSA Centers of Excellence, are referred to counseling for issues ranging from anxiety and depression to stress management and suicidal thoughts. Unfortunately, it is estimated that only between



15 and 25 percent of those referred for counseling actually seek treatment.

"By partnering with American Well, we are confident that we can greatly improve access to care for

families impacted by the challenging mental health nature of HD," said **Louise Vetter**. "Thanks to the generous support from Teva we are able to provide free telehealth appointments with professionals who have HD expertise. This fills an urgent gap in care and removes the barriers of cost, geography and convenient scheduling that too often keep families from seeking the help they need."

To utilize HDSA's free telehealth portal, visit **www.hdsa.amwell.com** or download the free **Amwell® app** and use the codes HDSA or HD to access the Huntington's disease practice. On the site, patients can schedule personal appointments with social workers and psychologists licensed in their state. **The session is free**

**for families affected by HD, and no insurance is required.**

### HDSA Partnered with the HealthWell Foundation to Assist Medicare Patients

The **HealthWell Foundation®**, an independent non-profit that provides a financial lifeline for inadequately insured Americans, opened a new fund that provided copayment and premium assistance to eligible Medicare patients living with Huntington's disease. The fund provided up to \$10,000 in assistance to Medicare patients who had annual household incomes up to 500 percent of the federal poverty level. The fund assisted Huntington's disease patients in accessing critical medications for treatment of their disease.



"We are delighted to have had a fund dedicated to assisting individuals with their treatment costs for Huntington's disease," said **Krista Zodet**, HealthWell Foundation President. "Huntington's is a deadly disease for which there is no cure. Dealing with the financial stress of being able to afford out-of-pocket costs to treat this devastating disease can be overwhelming for both the patient and their families. We are honored that our donors recognized the need for this critical financial lifeline to ease some of the burden these patients have to endure."

# HDSA 2017 Mission Reports

# Education Report

by Debra Lovecky, MS

2017 proved to be an exciting and thought-provoking year for both lay and professional education at HDSA. Continuing partnerships with both the **American Occupational Therapy Association (AOTA)** and the neurology division of the **American Physical Therapy Association (APTA)** yielded more qualified community-based therapists in the field for our HD families. In year two of our

partnership, more than 200 members of AOTA took advantage of the free-four part accredited continuing education course, developed by HDSA and offered on the AOTA website. Likewise, in year three, members of APTA continue to visit the HDSA website to learn about HD and earn certificates of completion for continuing education credits in their state.



This year also saw the development and launch of a three-part online accredited course on HD for community-based primary care providers, neurologists and psychiatrists. Partnering with **Medscape** and the **University of Alabama Birmingham**, HDSA provided guidance in faculty selection and content so that over the three part series, 14 of our HDSA Center of Excellence directors will have shared their knowledge and HD expertise in the areas of diagnosis, treatment options and the benefits of a multidisciplinary team approach to care. This program has been made possible through an unrestricted educational grant to Medscape from **Teva Pharmaceuticals**.

In the area of lay education, HDSA was able to provide funding for more than 50 field-based educational events that ranged from guest speakers at support groups to full-day, multi-track state conventions. More than 2,300 HD family members and healthcare professionals attended these events. New for 2017 were workshops on genetic testing and the National Youth Alliance. HDSA thanks Teva for their generous unrestricted educational grants which made this program possible.



*Debra Lovecky, MS is Director of Programs, Services and Advocacy at Huntington's Disease Society of America.*

# Youth Programs Report

by Jennifer Simpson, LCSW

This year was an incredible year for youth programming and support for the HD community. With the introduction of three **Regional Youth Retreats** in 2016, opportunities for support, education and community grew exponentially for young people impacted by Huntington's disease. In 2017, we added an additional Retreat in the South-east region, partnering with the **HDSA Center of Excellence at Ochsner Health in New Orleans**.

In 2016, **HDSA's National Youth Alliance (NYA)** reached 45 young people through our Regional Youth Retreats. This year that number jumped to 83, and we hope that number can continue to grow in 2018. The NYA also committed to working with not only those in the youth community in the United States, but around the world by creating connections between the NYA board and **Young People Affected by Huntington's Disease (YPAHD)**, the youth support program for the **Huntington's Society of Canada** and furthering our partnership with **Huntington's Disease Youth Organization (HDYO)** for the **North American Youth Camp**. The NYA also had an incredible experience at **HDSA's 32<sup>nd</sup> Annual Convention**, creating a comprehensive set of workshops for young people impacted by HD, including discussions about mental health, genetic testing, survivor's guilt and dealing with grief and loss. The NYA funded a record 53 scholarships to convention and was able to raise more than \$12,000

to fund scholarships for young people for the 2018 Convention in Los Angeles.

The NYA continues to grow its support programming for young people with generous sponsorship from **Teva Pharmaceuticals** and the HD community. We can't wait to see what 2018 brings!



*Jennifer Simpson, LCSW is Manager of Advocacy and Youth Programs at Huntington's Disease Society of America.*



# Advocacy Report

by Jennifer Simpson, LCSW

With the shift in administration came shifts in priorities — including opportunities for change in the areas of healthcare reform, research funding and the **HD Parity Act**. Although 2017 was complex, it did not deter HDSA's effort to have an impact on Capitol Hill.

The first half of the year saw several attempts at healthcare reform, but sadly none of which maintained whole current protections for individuals and families with pre-existing conditions. Since the options presented would not have made healthcare more robust or more affordable for families with complex conditions, HDSA joined hundreds of advocacy organizations and our partners at the **National Health Council** to oppose BCRA, AHCA and Cassidy-Graham. The HD community made their voices known as well by writing more than 3,000 messages to Members of Congress regarding Healthcare reform. As always we are hopeful that healthcare reform is possible, and can be done in a way that doesn't overly burden those with complex pre-existing conditions like Huntington's disease.

We also reintroduced the **Huntington's Disease Parity Act (HR 2589/S1197)** in the House and Senate in 2017. This bill was brought forth again by our tireless champions in the House,



**Representatives Pascrell (D-NJ) and Kinzinger (R-IL)**, and our leaders in the Senate, **Senators Cassidy (R-LA) and Gillibrand (D-NY)**. Although this is a difficult climate for any healthcare related legislation, HD advocates rallied to bring on new and returning co-sponsors to the bill.



We also saw new advocates join the fight and fly into Washington D.C. to storm the Hill and become **"HD Super Advocates"** for the Parity Act. With funding from **Teva Pharmaceuticals**, nearly 90 folks impacted by HD joined HDSA Staff and CEO **Louise Vetter** for a marathon day of meetings to educate, inform and advocate for the HD Parity Act. Advocates attended 168 meetings in a single day, and left quite the impression on legislators, with more than 30 of them signing on as co-sponsors since the fly-in. In 2017, as always, HD Advocates showed how mighty their impact can be.



*Jennifer Simpson, LCSW is Manager of Advocacy and Youth Programs at Huntington's Disease Society of America.*

# Services & Support Report

by Anne Leserman, LCSW

2017 was another busy and productive year for services provided to families throughout the country. **Social workers in HDSA Centers of Excellence, Chapters, Regions and other HD clinics assist families in 45 states and across their borders**. HDSA again received extra funding to bring social workers together not only at Convention for professional training but also at two other regional meetings in New York City and Atlanta. These educational events help social workers provide the best and most up-to-date information on assisting HD families with HD concerns. The national HDSA office continues to provide a **Helpline** for families and to refer to the Chapter and Regional social workers who respond to thousands of requests for information about HD, provide supportive counseling, and answer questions about genetic testing, long term care placement, disability and referrals to local resources. Social workers interact with professionals in their communities, including presentations to students of medicine, genetic counseling, social work, and behavioral health, as well as law enforcement personnel. Social workers also assist in educational day events, provide in-services to long-term care facilities or other health agencies, and participate in NYA retreats.



Many families find support and a listening ear at **HDSA support groups** available in 45 states. This year we piloted **online support groups** for caregivers and those at-risk for HD. We hope to expand the number of online groups in the coming year. Groups help families understand and normalize the symptoms that can occur in HD persons and benefits are felt both by caregivers and HD persons. Individual counseling sessions were also offered through **AmWell**, and many took advantage of free counseling sessions to get assistance from mental health professionals.

All of these services can be found through the HDSA website at **HDSA.org/locate**.



*Anne Leserman, LCSW is the Assistant Director of Community Services at Huntington Disease Society of America*

# Research Report

by George Yohrling, Ph.D.

## Building a Road to a World Free of HD

“A world free of Huntington’s disease.” That is the vision of HDSA. Those six simple words describe a place all of us in the HD community would like to see. Making our vision a reality requires more than words and dreaming. It requires resources, strategic planning, trial and error and collaboration where everyone rolls up their sleeves to do their part. The breakthroughs in developing treatments for HD that we seek are now closer than ever. This year in the clinic we saw exciting progress towards therapies for HD, including the first successful safety trial of a huntingtin-lowering drug. I am confident that if we focus our efforts on four key areas, disease modifying therapies for HD can provide the relief for which families yearn.

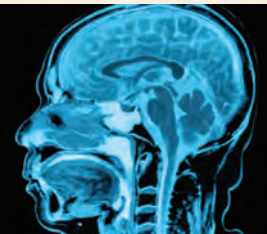
The road to a world free of HD must begin with a focus on the patient. There is no more important patient study than **Enroll-HD**. This year the Enroll-HD observational platform enrolled its 14,000th participant and expanded to 15 countries. In 2017, research on thousands of human samples from Enroll-HD and similar observational studies allowed researchers to identify new drug targets that may be able to halt the onset of HD symptoms. Enroll-HD’s open-access database is allowing researchers worldwide to answer questions about HD that simply were not possible until now. The potential of Enroll-HD is so great that HDSA has incorporated participation into our **Centers of Excellence** program.

## HD Human Biology Project

HDSA has been seeking to better understand HD in people with our flagship research program, the **HD Human Biology Project**. Since 2013, HDSA has invested more than \$3.6 million in this program. The research we support is all patient-centric and done in collaboration with HD clinics from around the globe with the goal of understanding HD in the only place it naturally occurs — in humans.

## HD-COPE

The real world perspective of the HD patient and caregiver will be an essential component in the development of meaningful therapies. To better provide this perspective to drug companies, **HDSA**, the **Huntington Society of Canada** and the **European Huntington Association** launched the **HD-Coalition on Patient Engagement (HD-COPE)** in 2017. The purpose of HD-COPE is to add quality to all aspects of clinical trials through patient representative input. At HDSA, we know that pharmaceutical and biotechnology companies, as well as regulatory agencies like the FDA, have



a unique responsibility and opportunity to work with families to ensure that new treatments offer meaningful benefit to HD families. Together, Enroll-HD, the Human Biology Project, and HD-COPE are critical pieces of HDSA’s patient-focused strategy to support impactful HD research that will help build the road to a world free of HD.

## HDSA Fellowship Grants

Joining the patients and families on this journey will be our HD scientists. HDSA strongly believes it is our responsibility to ensure the next generation of HD scientists are prepared for what lies ahead. In addition to continuing the Human Biology Project, in 2017 HDSA awarded two **Berman-Topper Family HD Career Development Fellowships** to **Dr. Tamara Maiuri** (McMaster University) and **Dr. Sarah Hernandez** (University of California at Irvine). These three year grants are unlike any young investigator award in the world, providing \$80,000



Dr. Tamara Maiuri



Dr. Sarah Hernandez

of annual support for three years. HDSA awarded four **Donald A. King Summer Research Fellows** in 2017, a record number. Investing in these young scientists now should produce tangible benefits for the HD community in the future.

## HDSA Centers of Excellence

The third area of focus is on the expansion of care and research sites around the country. All people are entitled to receive expert care for their HD no matter where they live. To address this, HDSA has more than doubled the number of **HDSA Centers of Excellence (COEs)** in the US to 41 (plus an additional 5 partner sites) since 2015. At these 46 clinics, HD patients can receive multidisciplinary care and participate in HD research. HDSA must continue to provide adequate resources to our COEs to ensure they have the infrastructure in place to handle the HD clinical trials of the future.



## HD Clinical Trials

The final leg of the journey will require novel drugs and rapidly recruiting clinical trials. In 2017, we all celebrated the approval of a second drug to combat the symptoms associated with HD. In April, the FDA approved **Teva Pharmaceuticals** application for **Austedo®** to

treat HD chorea. The importance of adding a new weapon to our clinical arsenal cannot be overstated.

We are encouraged by the December 2017 announcement from **Ionis Pharmaceuticals** that the **first ever antisense oligonucleotide drug was found to successfully lower huntingtin in addition to being safe and tolerable in a Phase 1b/2a clinical trial**. This is a *tremendous* step forward for the HD community, giving us hope for the future of this therapy and providing additional optimism for two new clinical studies that specifically target the expanded huntingtin gene.

Finally, the community must be ready to answer the call for research volunteers to get these disease-modifying trials completed as quickly as possible. There are more than six companies that are in the clinic, or will be shortly, testing huntingtin-lowering treatments. To help facilitate participation, HDSA will continue to collaborate with our partners in HD education to

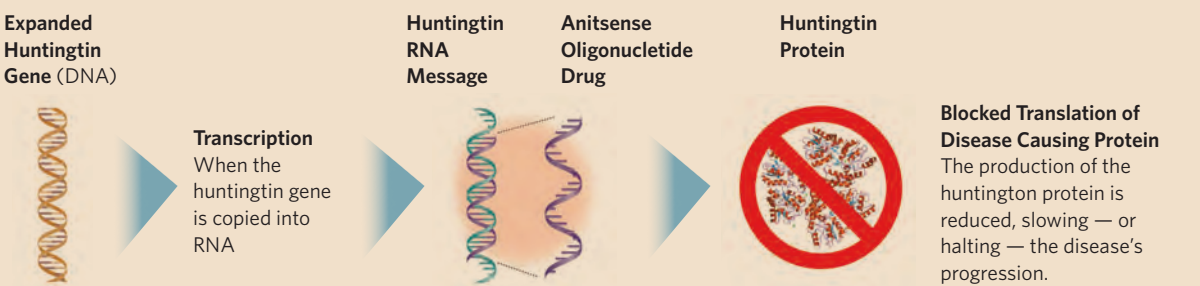
increase utilization of **HDTrialfinder.org** and its accompanying call center, matching potential participants with studies in their area. The biggest hurdle to completing clinical trials to assess new therapies is how much time it takes to recruit; time is simply a luxury HD patients do not have.

As I look back on 2017, I am genuinely excited by the progress that has been made. There are scientific breakthroughs happening now in HD, with more around the corner, and it gives me hope that 2018 will bring us much closer to a “world free of Huntington’s disease.”



George Yohrling, Ph.D. is the Senior Director, Mission and Scientific Affairs at Huntington Disease Society of America

## How Ionis’s Antisense Oligonucleotide Drug Works



Source: Ionis Pharmaceuticals

**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.*

**HDSA Leadership**

**HDSA Board of Trustees**

**Arik Johnson, Psy.D.**  
Chairman of the Board

**E.J. Garner**  
Chair-Elect

**Daniel S. Vandivort**  
Treasurer

**Jennifer Leyton**  
Secretary

**Jang-Ho Cha, M.D., Ph.D.**  
Past Chair

**Dan Brennan**

**Stacy Coen**

**Jenne Coler-Dark**

**Gerald Francese, Esq.**

**Michelle Gray, Ph.D.**

**Donald S. Higgins, Jr., M.D.**

**Bill Kline**

**Theresa Srajer**

**Arvind Sreedharan**

**Victor Sung, M.D.**

**HDSA Staff Leadership**

**Louise Vetter**  
President &  
Chief Executive Officer

**George Yohrling, Ph.D.**  
Senior Director,  
Mission & Scientific Affairs

**Christopher Cosentino**  
Director of Marketing  
and Communications

**Nancy A. Rhodes**  
Director of Field Development  
and Operations

**SEE YOU JUNE 7-9 IN L.A.!**



**SAVE THE DATES!**

Join us for the **33<sup>rd</sup> Annual  
HDSA Convention** in the  
city of stars —Los Angeles,  
California — at the  
Los Angeles Airport Marriott.



**JUNE 7-9, 2018 / LOS ANGELES, CA**



[www.hdsa.org/convention](http://www.hdsa.org/convention)



**50 YEARS OF SERVICE**  
**1967-2017**

505 Eighth Avenue  
Suite 902  
New York, NY 10018

800-345-HDSA  
212-242-1968 (National Office)

[www.hdsa.org](http://www.hdsa.org)

