“She Came Along to Me”
Woody Guthrie’s love song to his wife and
HDSA founder Marjorie Guthrie

2017 Year In Review
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 tide 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.
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 50th Anniversary Kick Off Event
On October 25th, 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.

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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.”

2017 Highlights

Pope Francis’ Special Audience with the Huntington’s Disease Community
On May 18, HDSA served as an integral partner to a global coalition of Huntington’s disease advocates that came together under the HDdennomore (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 HDdennomore team includes Charles Sabine, Elena Cattaneo, Ignacio Munoz-Sanjuan, Claudia Perandones, Louise Vetter and many others!

For more information please visit www.HDdennomore.com

HDSA Center of Excellence Program Expands to 41 Sites Across the United States
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For more information please visit www.HDdennomore.com
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.

HDSA’s New York City Marathon Team Breaks Record in 2017
Twenty-seven runners from 13 states raised more than $166,000 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 12th 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 Bordino, Elizabeth Christian, Melody Coker, Brian Crunk, James Del Carpio, Maryann Emerick, Anne Ericson, Heather Faragut, Sydney Green, Dawn Goldmine, Michelle Kahn, Lawrence Konick, Nicole Lodesma, Karen Milik, Carl Moe, Lindsay Morrison, Ben Paul, Christopher Pfaff, Jason Reaser, Gail Schuber, Kari Scott-Ciota, Josh Silverstein, Miranda Spencer, Margaret Swartz, Guillerome Torres and Deborah Zimmermann.

Thank you to everyone who ran and supported TEAM HDSA!

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.

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 diseases,” 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 battles this devastating brain disorder.

To watch Her Mother’s Daughter for free, please visit HDSA.org/HMDfilm.
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.

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.

SAVE THE DATES!
The 33rd 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.
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!

**Region Highlights**

**UPPER MIDWEST REGION**
- Minneapolis Team Hope Walk
  Edina, MN
  Minnesota Chapter
  $26,400
- Omaha Team Hope Walk
  Omaha, Nebraska
  Omaha Affiliate
  $20,400
- Be the Hope Reception
  Saint Paul, MN
  Regional Event
  $24,600

**GREAT LAKES REGION**
- A Night in Venice
  Cleveland, OH
  Regional Event
  $191,500
- Illinois Team Hope Walk
  Naperville, IL
  Illinois Chapter
  $51,600
- Liberty Team Hope Walk
  Liberty, MO
  Regional Walk
  $150,000

**NEW YORK / NEW JERSEY REGION**
- New York City Team Hope Walk
  New York, NY
  Greater New York City Chapter
  $77,700
- Corks & Forks Celebration of Hope
  Albany, NY
  Albany NY Chapter
  $71,300
- Northern New Jersey Team Hope Walk
  Edison, NJ
  New Jersey Chapter
  $67,900
- D.C. Metro Golden Gala
  Chevy Chase, MD
  D.C. Metro Chapter
  $163,000
- Maryland Crab Feast
  Harford County Maryland
  Central Maryland Affiliate
  $27,400
- Maryland Team Hope Walk
  Baltimore, Maryland
  Central Maryland Affiliate
  $25,000

**SOUTHEAST REGION**
- 26th Annual HD Triathlon
  Miami, FL
  South Florida Chapter
  $17,200
- Kevin Butler
  “Golf for a Cure” Tournament
  Westwood, GA
  Georgia Chapter
  $30,500
- Georgia Team Hope Walk
  Decatur, GA
  Georgia Chapter
  $34,300

**NEW ENGLAND REGION**
- New England Celebration of Hope Gala
  Newton, MA
  Regional Event
  $11,000
- Boston Team Hope Walk
  Boston, MA
  Massachusetts Chapter
  $77,100

**PACIFIC SOUTHWEST REGION**
- An Evening with Chris Berman — Celebration of Hope Gala
  San Diego, CA
  San Diego Chapter
  $35,500
- San Francisco Team Hope Walk
  San Francisco, CA
  Regional Event
  $84,400
- Shoot For A Cure
  San Diego, CA
  San Diego Chapter
  $61,300
- Denver “Heroes vs. Villains” Team Hope Walk and 5K Run
  Denver, CO
  Rocky Mountain Chapter
  $32,900
- North Texas Team Hope Walk
  Plano, TX
  Greater North Texas Affiliate
  $26,900
- Central Houston Team Hope Walk and 5K Run
  Houston, TX
  Houston Affiliate
  $24,600

**SOUTHWEST REGION**
- Seattle Team Hope Walk
  Seattle, WA
  Washington State Chapter
  $49,500
- Boise Team Hope Walk
  Boise, ID
  Regional Event
  $15,000
- Spokane Team Hope Walk
  Spokane, WA
  Washington State Chapter
  $7,763
- A Night in Venice
  Saint Paul, MN
  Regional Event
  $24,400
- Omaha Team Hope Walk
  Omaha, Nebraska
  Omaha Affiliate
  $15,000
- Shoot For A Cure
  San Diego, CA
  San Diego Chapter
  $61,300

**SPECIAL THANKS TO OUR NATIONAL EVENT SPONSORS**
- Asclephius Healthcare Resource
  National Team Hope Sponsor
- Biogen
  National Team Hope Sponsor and National Celebration of Hope Sponsor
- Teva Neuroscience
  National Team Hope Sponsor
- Ascletis Healthcare Resource
  National Team Hope Sponsor
- Grit Science
  NJ Team Hope Walk Sponsor
The Casual Tap is owned by Steve Magana, who is a full-time Chicago fire fighter. Jon Taffer went to Chicago, Illinois to try to decide to redesign Jon and his crew inherited HD. 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 benefiting HDSA. Jon also made a personal donation to support our programs and services to the HD community.

The Guthrie Sessions at HDSA

Although Woody Guthrie died from HD complications in 1967, HDSA has stayed true to its music roots to continue the legend. The Guthrie Sessions at HDSA continue to attract incredible talent to help build HD awareness on social platforms. The Guthrie Sessions at HDSA have continued to attract incredible talent to build HD awareness on social platforms. This year’s performances included stars from the hit show, Fast & Furious, of the films, such as Sung Kang, star of the film. 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 (PSRA) worn 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 wrist bands and Huntington’s disease PSA fliers 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 Kaykyn Oren, 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 Omaline Affiliate accepted the 9HDBlueHoseChallenge at this 19th Annual Team Hope Walk. Partnering with the Omaha Fire Department, the HDSA Omaha Affiliate had a record-setting 120 walkers take the challenge!

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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
- A listing of important related links and suggested apps and games for HD information and brain health
- “HDNavigator” or “HDSA” search feature 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.

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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 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 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.
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.

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 Southeast region, partnering with the HDSA Center of Excellence of 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 (YPHA). 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 32nd 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!

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

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

17 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/localsearch.
Building a Road to a World Free of HD

“[A] world free of Huntington’s disease.” That is the vision of HDSA. Three 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 see 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 the four key areas, disease modifying therapies for HD can provide the relief for which families yearn.

A decade of clinical trials through HD-COPE

The worldwide HD population has grown exponentially — in humans. The production of the huntington gene is blocked — the disease’s progression is reduced, slowing — or halted — the disease’s progression. The production of the huntingtino gene

**Building a Road to a World Free of HD**

**Research Report**

by George Yohrling, Ph.D.

**Huntington Human Biology Project**

HDSA has been seeking to better understand HD in people with our flagship research program, the Huntington 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 driven 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 Association of the United Kingdom, and the European Huntington Association launched the HD-COPE (HD-Clinical Patient Engagement) in 2017. The purpose of HD-COPE is to add quality to all aspects of clinical trials through patient representative input. At HDHDSA, 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 Huntington 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 Huntington Human Biology Project, in 2017 HDSA awarded two Orange-Topper Family HD Career Development Fellowships to Dr. Tamara Maiuri (McMaster University) and Dr. Sarah Hernandez (University of California at Irvine). These threeyear grants are unlike any young investigator award in the world, providing $80,000 of annual support for three years. HDSA awarded four Donald A. King Summer Research Fellowships in 2017, a number increasing in these young scientists may now 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 care and research are entitled to receive expert care for 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 4 additional partner sites as of 2020). At these 45 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 celebrated the approval of a second drug to combat the symptoms associated with HD. In April, the FDA approved Teva Pharmaceuticals application for Ausberto® 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 growth.

**HD in People with HD with HDSA**

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 I give me hope that 2018 will bring us much closer to a “world free of Huntington’s disease.”
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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.

Save the Dates!
Join us for the 33rd Annual HDSA Convention in the city of stars —Los Angeles, California — at the Los Angeles Airport Marriott.

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