Looking Back. Moving Forward.
Looking Back. Moving Forward.

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 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, continue to provide more resources to HD families in need and make that one day without HD… today.

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. (Visit www.HDSA.org and mark your calendar for our 34th Annual HDSA Convention in Boston this June!)

Thank you,

Louise Vetter, President and Chief Executive Officer
HDSA Centers of Excellence Expand to 43 Sites

The 2018 HDSA Centers of Excellence program expanded to 43 Centers in 2017. Since 2015 the program has grown from just 20— an 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 to a larger number of families affected by Huntington’s disease.

The HDSA Centers of Excellence provide an elite team approach to Huntington’s disease care and research. Patients benefit from expert neurologists, psychiatrists, therapists, counselors and other professionals who have extensive experience working with families affected by HD and who work collaboratively to help families plan the best HD care program throughout the course of the disease. Applications to become an HDSA Center of Excellence are open annually to all clinics in the United States with a clear commitment to bringing high-quality, comprehensive care and access to clinical research.

2018 Highlights

With the continued growth of the program, the HDSA is bringing more ‘boots on the ground’ to support HD affected families across the United States with care locations in the Pacific, Northern, Southern, and Northeast regions plus the District of Columbia. In addition, four Centers have partner sites to expand care to Arkansas, Tennessee, Mississippi, and Alabama. This year, HDSA awarded a total of $1,264,250 to the Centers of Excellence program, an increase of $104,500 from last year.

“HDSA’s Center of Excellence program is the cornerstone of comprehensive care for families affected by Huntington’s disease,” said Louisa Vetter, HDSA’s President & Chief Executive Officer. “With multi-disciplinary care teams that integrate medical, mental health professionals, genetic counselors, social workers and more, an HDSA Center of Excellence means a medical ‘home’ for HD families and a place where their complex needs can be addressed cooperatively and with compassion. Now with forty-three centers nationwide, many families have access to high-quality HD care.”

E.J. Garner

E.J. Garner appointed Chair of the National Board of Trustees

Tamara Alán, Dr. Leslie Thompson and Dr. Vicki Wheelock join HDSA’s Board of Trustees

The Huntington’s Disease Society of America (HDSA) National Board of Trustees has elected E.J. Garner as new Chair replacing Dr. Arth Johnson who completed his two-year term. Dr. Johnson will now serve as Past Chair for a two-year term, and Dr. Victor Sung, Director of the HDSA Center of Excellence at the University of California at Berkeley, has been appointed as new Vice-Chair.

“I am honored to serve the Huntington’s Disease Community for another two years,” said Dr. E.J. Garner. “I have been a part of this amazing organization for the last 20 years and have always been impressed with the work HDSA and our Center of Excellence partners do to help families affected by HD. As Chair of the HDSA Board of Trustees, I am excited to lead our organization towards our vision of a world without Huntington’s disease. I look forward to working with my fellow Board members to advance the mission and support the important work we do.”

E.J. Garner has been active in HDSA’s volunteer leadership and has served on HDSA’s National Board of Trustees since 2015. She was on the board of HDSA’s National Chapter from 2013 to 2015. She was named the Chapter’s Volunteer of the Year in 2013 and was recognized as one of the top fundraisers of HDSA Team Hope Walk in 2013 and 2015. In tribute to her son and grandson and in an effort to raise awareness and funds for the fight against HD, E.J. embarked on the 5,046-mile Camino de Santiago pilgrimage in mid-August 2015. Walking the route of 2,181 miles, she raised more than $16,000 for HDSA Team Hope Walk. E.J. is currently working the 2,165 miles of the Pacific Crest Trail (approximately 800 miles). E.J. has been deeply affected by Huntington’s disease. She is the grandmother of twin granddaughters who are at-risk of HD. Her first husband passed from Huntington’s disease in 2002, and her son Scott died at age 44 from complications of HD in 2015. Additionally, her grandson, brother to her granddaughters, Matthew, died at age 6 from Juvenile HD in May 2008. A long-time resident of Southern California, E.J. recently returned to her native West Virginia with her husband, Art, to be close to her grand- daughter and daughter-in-law. After 40 years with Toyota Motor Sales, U.S.A., Inc., she retired from a career of various management positions including, administration, marketing, merchandising, and distribution/logistics. E.J. holds a Bachelor’s Degree from Indiana University, and a Master’s Degree from the University of Redlands in California.

It is an honor and a privilege to be appointed Chair of HDSA’s Board of Trustees,” said Mrs. Garner. “The Huntington’s Disease Society of America is comprised of doctors, scientists, researchers, family members and others committed to finding a cure for Huntington’s Disease. Having lost a son and grand- son to HD, I feel a special responsibility to help represent the thousands who face the challenges of the disease every day. Just as those fighting HD need a place to turn for comfort and support, I hope to inspire others to support and get involved with their local HDSA Chapters and Affiliates. As a advocate in research and treatments reach market and the hope for a cure grows, HDSA must continue to grow and continue to assist those dealing with the disease on a daily basis, those with HD and the families and friends that support them. I also look forward to working with HDSA’s Youth Alliance and supporting them and inspire others to get involved in the battle against HD.”

In addition to Mrs. Garner’s appointment, Kamran Alam, Dr. Leslie Thompson and Dr. Vicki Wheelock have recently been elected to join HDSA’s National Board of Trustees. Mr. Alam is currently the President of the Huntington’s Disease Society of America. Mrs. Thompson has been appointed Chair-Elect of HDSA’s National Youth Alliance and supporting them to get involved in advisory roles within the organization.

Kamran Alam

Dr. Leslie Thompson

Dr. Vicki Wheelock
Enroll-HD Reaches 20,000 Participants Worldwide!
Enroll-HD’s 20,000th 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.

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

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 Krasimir Chisidoma. The evening included an incredible auction, delicious food and live entertainment. Celebrities such as Scott Porter, Jason Ritter, Tyler Ritter, Caitlin Carver, Kate Moyer, Anique Coletti, Jeff Meacham; and many more were on-hand to generate much-needed funds for the HD family.

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 authors to scientists 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 looked off HD Awareness Month with Night of the Machine—a concert in Los Angeles that raised nearly $200,000! The event was held at Neuehouse in Hollywood and featured the music heritage. Martha was joined on stage by her father, Loudon Wainwright III. The evening included an incredible auction, delicious food and live entertainment. Celebrities such as Bradley Cooper, Jason Ritter, T yler Ritter, Caitlin Carver, Kate Moyer, Anique Coletti, Jeff Meacham; and many more were on-hand to generate much-needed funds for the HD family.

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 $240,000 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.

HDSA’s NYC MARATHON TEAM ROSTER:

Photo: Mark J. Rebilas, USA TODAY Sports

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Here’s The Deal
HDSA’s Here’s the Deal is a weekly 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, LCMW, Here’s The Deal provides incredible insight into subjects such as suicide, survivor’s guilt, relationships and much more.

Photo: Mark J. Rebilas, USA TODAY Sports

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This Week in HD Research
In 2018 HDSA launched This Week in HD Research, a weekly blog is curated by HDSA’s Dr. Leora Fox which provides updates on HD science and meaningful science news from around the world. To read the latest post visit HDSA.org/blog.
The Huntington’s Disease Society of America (HDSA) hosted its 33rd Annual Convention on June 7th-9th at the Los Angeles Marriott in California. The HDSA Convention is the world’s largest conference for Huntington’s disease. Fifty years ago Marjorie began her crusade to ‘do something’ about this devastating brain disorder and encouraged families to follow in Marjorie’s footsteps to get involved and “do something”.

During the entire Convention there was a clear message to follow in Marjorie Guthrie’s footsteps to ‘do something’ about Huntington’s disease. Families affected by Huntington’s disease would like to thank everyone who supported and attended the 33rd Annual HDSA Convention, said HDSA’s President & CEO Louise Vetter. “Throughout the entire Convention there was a clear message to follow in Marjorie Guthrie’s footsteps to ‘do something’ about this devastating disease. Fifty years ago Marjorie began her crusade against HD, and today we continue her legacy by bringing together the entire community to provide help and hope to all families affected by Huntington’s disease.”

The HDSA Convention kicked off on Thursday with its ceremonial Team Hope Walk and a carnival-themed Welcome Reception. Attendees were greeted by a surprise video greeting from actress Dallas Howard who donated four tickets to the LA premiere of her latest film, Jurassic World: Fallen Kingdom.

On Friday morning’s opening ceremony featured powerful keynotes from Anna Canoni and Bill Johnston, respectively. Anna, who is the granddaughter of Woody and Marjorie Guthrie, shared her family story on how the Guthries were impacted by HD and Marjorie’s extraordinary determination to establish the Committee to Combat Huntington’s Disease (now known as the Huntington’s Disease Society of America) fifty years ago. San Diego Padres’ executive and HD family advocate Bill Johnston then discussed his family’s battle against this devastating brain disorder and encouraged families to follow in Marjorie’s footsteps to get involved and “do something”.

Immediately following the Opening Ceremony, the HDSA Convention featured workshops led by world-class researchers, caregivers, social workers, clinicians and other experts. For Friday night at the annual HDSA National Youth Alliance (NYA) Talent Show attendees were entertained with music, dance, standup comedy and magic. The show raised more than $30,000 to support the NYA Convention Scholarship Fund which sends youth to Convention each year.

The much-anticipated Research Forum on Saturday featured a first-of-its-kind panel which presented the history of the discovery of the HD gene and how it has led to the development of a promising new potential therapy for HD using antisense oligonucleotides. The panel included Dr. Jim Gusella, Dr. Anna Smith, Dr. Holly Kordasiewicz, Dr. Robert Pacifici, Dr. Doug Macdonald, Dr. Ed Wild, Dr. Bist Lurie, Erik Luntgren, Dr. George Vohringer and HD family advocate Amy Fedele.

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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!

### Twin Cities Team Hope Walk
- **Twin Cities Team Hope Walk**
- **Minnesota Chapter**
- **$48,957**

### New England Region
- **Celebration of Hope**
- **Regional Event**
- **$60,000**

### 20th Annual Cure HD Golf Tournament
- **Tennessee Chapter**
- **$418,930**

### Sioux Falls Team Hope Walk
- **South Dakota Chapter**
- **$45,572**

### Iowa Hoop-A-Thon Tour
- **Iowa Chapter**
- **$25,729**

### New York City Team Hope Walk
- **Greater New York Chapter**
- **$93,600**

### New Jersey Team Hope Walk
- **New Jersey Chapter**
- **$88,193**

### 2018 Albany Wine Tasting — Corks & Forks
- **Albany Chapter**
- **$83,400**

### New York / New Jersey Region
- **Celebration of Hope**
- **Regional Event**
- **$60,000**

### Upper Midwest Region
- **Twin Cities Team Hope Walk**
- **Minnesota Chapter**
- **$48,957**

### Great Lakes Region
- **Illinois Team Hope Walk**
- **Illinois Chapter**
- **$109,500**

### New England Region
- **Celebration of Hope**
- **Regional Event**
- **$60,000**

### Pacific Region
- **San Diego Team Hope Walk**
- **San Diego Chapter**
- **$85,000**

### Midwest Region
- **San Diego Street To Cure HD**
- **San Diego Chapter**
- **$70,000**

### 6th Annual District of Columbia
- **Celebration of Hope — Derby Style**
- **Washington, D.C.**
- **Metro Chapter**
- **$38,360**

### Mid-Atlantic Region
- **Fast Track for a Cure**
- **Western Pennsylvania Chapter**
- **$20,200**

### Pennsylvania Region
- **Philadelphia Team Hope Walk**
- **Eastern Pennsylvania Chapter**
- **$18,300**

### South Central Region
- **Horus vs. Villains**
- **5K Run/Walk**
- **Rusty Mountain Chapter**
- **$42,700**

### Southeast Region
- **27th Annual Cure HD Golf Tournament**
- **Tennessee Chapter**
- **$408,950**

### Special thanks to our National Events Sponsor
- **Teva Neuroscience**

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### New England Region
- **Celebration of Hope**
- **Regional Event**
- **$60,000**

### Boston Team Hope Walk
- **Massachusetts Chapter**
- **$45,000**

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- **$109,500**

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- **New Jersey Chapter**
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### 2018 Albany Wine Tasting — Corks & Forks
- **Albany Chapter**
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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 this year also marked the 25th anniversary of the identification of the huntingtin gene. The year 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 U.S. The study will be called the GENERATION-HD1 study. The study name and Roche/Genentech team are inspired by HD families with the hope that “this will be the last generation to suffer” from the ravages of this hideous disease. News of this study has grabbed the attention of the global HD community. While the light of hope now shines brighter for all of us, we must not lose sight that much work remains before a finish line comes into sight.

GENERATION-HD1 and other HD trials will be long and require an unprecedented amount of commitment from not only HD families, but also the clinic staff that will run these studies. We know that the demand to participate in GENERATION-HD1 will outpace available spots, and this will undoubtedly be devastating news to many families. However, we are fortunate that there are many other companies currently testing or making plans to test innovative HD treatments.

On December 19th, Roche/Genentech announced the US and Canadian locations for GENERATION-HD1 to test efficacy of the huntingtin-lowering therapy RG6042. This will be a two-year study in people with early diagnosed HD. It will involve monthly lumbar punctures (spinal injections) to deliver RG6042 or a placebo, as well as clinical tests and scans to understand the effect of the drug on HD symptoms. Around 660 people age 25-65 will be recruited at approximately 90 sites across the world, including 20 sites in the U.S. (see list below) and six in Canada.

As I look back on 2018, I am overwhelmed by the progress that has been made by the HD research community. When the calendar turns to 2019, I know that the HD families around the world will be ready to answer the call for brave research volunteers to get these disease-modifying trials complete quickly. The scientific breakthroughs of this past year give me hope that 2019 will bring generations of HD families a step closer to seeing the finish line.

Thank you for all you do!

Research Report

BY GEORGE YOHRLING, Ph.D.

Expectcd Sites for GENERATION-HD1 Studies in the United States

| ALABAMA, Birmingham | University of Alabama | ARIZONA, Phoenix | Barrow Neurological Clinic |
| CALIFORNIA, Davis | University of California, Davis | CALIFORNIA, Palo Alto | Stanford University |
| CALIFORNIA, Santa Barbara | University of California, Santa Barbara | COLORADO, Denver | Rocky Mountain Movement Disorders Center |
| FLORIDA, Tampa | University of South Florida | ILLINOIS, Chicago | Northwestern University |
| MARYLAND, Baltimore | Johns Hopkins University | MASSACHUSETTS, Boston | Beth Israel Deaconess Medical Center |
| MISSOURI, St. Louis | Washington University | NEW YORK, Amherst | Dent Institute |
| NEW YORK, New York | Columbia University | PENNSYLVANIA, Pittsburgh | University of Pittsburgh Medical Center |
| TENNESSEE, Nashville | Vanderbilt University Medical Center | TEXAS, Houston | University of Texas Health Science Center |
| UTAH, Salt Lake City | University of Utah | VIRGINIA, Norfolk | Virginia Commonwealth University |
| WASHINGTON, Seattle | Evergreen Health | WASHINGTON, D.C. | Georgetown University |

Roche’s Erik Lundgren speaks at the Research Forum at HDSA’s 2018 National Convention.

George Yohrling, Ph.D. is HDSA’s Senior Director of Mission and Scientific Affairs.

George Yohrling, Ph.D.
BY JENNIFER SIMPSON, LCSW

Advocacy Report

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 Huntington’s Disease Society of America to fight against measures that would have negatively impacted families with Huntington’s disease. We fought against cuts to Medicare and fought successfully for increases to the NIH budget for neurodegenerative disease research. HDASA 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, HDASA and HD advocates worked to make sure that we are still making progress towards improving the lives of individuals and families impacted by Huntington’s disease. In 2018, we also said goodbye to our long-time Washington insider Jason Gromley. Jason worked with HDASA and the HD community for 7½ years advancing important legislation and regulatory initiatives to streamline access to Social Security Disability, Medicare and helping to forge important relationships within the FDA to help them better understand the needs of HD patients and their families. Although we miss Jason, we are excited to announce a new partnership with Catherine Finley and Thorn Run Partners, and look forward to continuing to make strides in 2019.

BY DEBRA LOVECKY, MS

Education Report

2018 continued to be an outstanding year for HDASA’s lay and professional educational efforts. In the area of lay education, HDASA 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 outstanding programming, the areas of both lay education, HDASA 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 outstanding programming, HDASA’s lay and professional educational efforts. In 2018, more than 1,000 HD family members travelled to Los Angeles, CA to attend HDASA’s 33rd Annual Convention which honored and commended HDASA’s 50 years of service to the HD community. In an inspiring keynote address by Dr. Victor Sung, Watrous Golden’s grand-daughter, recounted her family’s role in shaping the course of care for families by sharing stories and family photos of Marjorie and Woody. For those HD families who could not join us in Los Angeles, HDASA also streamed and recorded ten workshops that can be viewed online at: HDASA.org/convention. In the area of professional education, HDASA travelled to Salt Lake City UT to conduct a day long training session on HD as part of the Occupational Therapy Association (AOTA) pre-conference institute. Speakers included Sandra Kostyk, M.D., Ph.D., HDASA Center of Excellence at the Ohio State University; Lisa Warren, OTR/L, HDASA Center of Excellence at the Ohio University; Jan Rowe, OTD, OTR/L, University of Alabama, Birmingham; K. Michelle Knoppe-Walshins, OTD, OTR/L, Mercy Baldwin University; Theresa Berner-Most, OTR/L, HDASA Center of Excellence at Ohio State University; and Anna Leserman, LCSW from HDASA. Since launching a four-part continuing education course in partnership with AOTA in 2016, almost 3,900 occupational therapists have registered for the course and AOTA has awarded almost 2,250 credits thus achieving HDASA’s goal of increasing access to knowledgeable community based occupational therapists. HDASA will be partnering with AOTA in 2019 to launch a new four-part course which will run for three years.

In the fall of 2017, HDASA partnered with Medscape and the University of Medicine and Dentistry of New Jersey, to launch the online course, ‘Management of HD’ with Drs. Victor Sung and Erin Furr-Stimming. The course was made possible through an unrestricted educational grant from Teva. HDASA is proud to have been a partner with UAB and Medscape and to have had the opportunity to feature so many of our outstanding HDASA Center of Excellence directors as part of the program.
2018 was a banner year for youth programs! We held four youth retreats across the country, bringing in 84 young people and their guardians to experience a weekend of community, education, laughter and healing. The National Youth Alliance (NYA) held retreats in Pittsburgh, Des Moines, New Orleans and Denver, partnering with local chapters and HDSA Centers of Excellence to make sure that our young people are getting the best information available from experts in the HD field. Sponsored by Teva, these retreats are at no cost to families, including travel and hotel stays for young people and their guardians. We look forward to bringing in some new sites in 2019, stay tuned to see when and where we’ll be in 2019!

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 onboarded and trained two social workers within the HDSA network, Jessica Marselik 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.

JENNIFER SIMPSON, LCSW is HDSA’s Senior Manager of Advocacy and Youth Programs.
SAVE THE DATE!
Join us for the 34th Annual HDSA Convention in historic Boston at the Marriott Boston Copley Place.
JUNE 27-29, 2019, BOSTON, MA
Register today at HDSA.org/convention

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HDSA’s Mission
To Improve the Lives of Everyone Affected by Huntington’s Disease and Their Families.

HDSA’s Vision
A World Free of Huntington’s Disease.