

*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](http://www.HDSA.org) and mark your calendar for our **34<sup>th</sup> Annual HDSA Convention in Boston this June!**)

Thank you,

**Louise Vetter,**  
President and Chief Executive Officer

## LOOKING BACK

ON 50 YEARS OF SERVICE TO THE HUNTINGTON'S DISEASE COMMUNITY

Throughout 2018, HDSA recognized 50 years of service to the HD community and paid tribute to the legacy of its founder, Marjorie Guthrie. In 1967, Marjorie founded the Committee to Combat Huntington's Disease (now known as the Huntington's Disease Society of America) after her husband and music icon Woody Guthrie died from HD when he was only 55 years old. Marjorie set out to "do something" about this devastating brain disorder that also threatened their children. Ms. Guthrie began her crusade against HD by traveling the world to meet with doctors, researchers, politicians and families to generate more awareness for Huntington's disease. Her extraordinary dedication to finding treatments and a possibly a cure for HD has led to so many advances in neuroscience putting scientists on a path to one day rid the world of HD.



## 2018 Highlights

### HDSA Centers of Excellence Expand to 43 Sites

The 2018 **HDSA Centers of Excellence** program expanded to 43 Centers from 41 in 2017. Since 2015 the program has grown from just 20—a 115 percent increase in four years. The HDSA Centers of Excellence are multi-disciplinary care teams with expertise in Huntington's disease that share an exemplary commitment to bringing comprehensive care.



With the continued growth of the program, HDSA is bringing more 'boots on the ground' to support HD affected families

across the United States with care locations in 30 States plus the District of Columbia. In addition, four Centers have partner sites to expand care in Oregon, California, 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 **Louise Vetter**, HDSA's President & Chief Executive Officer. "With multi-disciplinary care teams that include neurologists, 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 capably and with compassion. Now with forty-three centers nationwide, more families have access to high-quality HD care."



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 who share HDSA's commitment to high-quality, comprehensive care and access to clinical research.

Ms. Vetter added, "In addition to exceptional care, HDSA Centers of Excellence are on the frontlines of the development of new HD therapies. Each Center is required to support clinical research and most of them offer families direct participation in important observational studies and drug development trials. HDSA Centers of Excellence are the epitome of the help and hope that has guided our mission for fifty years."

### E.J. Garner Appointed Chair of the National Board of Trustees

*Kamran Alam, 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. Arik 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 Alabama at Birmingham, has been appointed Chair-Elect.



*E.J. Garner*

Mrs. Garner has been an active HDSA volunteer since 2006 and has served on HDSA's National Board of Trustees since 2015. She was on the board of HDSA's Orange County Chapter from 2008 to 2013 and served as Chapter President from 2010 to 2012. She was named the Chapter's Volunteer of the Year in 2011 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 554 mile Camino de Santiago pilgrimage in mid-August 2015. Walking the entire route with a 23-pound backpack, she raised more than \$16,000 for HDSA Team Hope Walk. Currently she is trekking the 21 California Missions 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, she recently moved to Olympia, WA with her husband, Art, to be close to her granddaughters 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 of Science degree from 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 Board is made up of a fantastic group of doctors, scientists, researchers, family members and others committed to finding a cure for Huntington's disease. Having lost a son and grandson 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 daily inspire me, I hope to inspire others to support and get involved with their local HDSA Chapters and Affiliates. As advances in HD 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 National Youth Alliance and supporting

their mission and inspire them to get involved in the battle against HD."

In addition to Mrs. Garner's appointment, **Kamran Alam**, **Dr. Leslie Thomson** and **Dr. Vicki Wheelock** have recently been elected to join HDSA's National Board of Trustees. Mr. Alam is currently the Vice President, Finance and Treasurer at AveXis, Inc., a Novartis Company in Bannockburn, Illinois. Dr. Thompson is a world-renowned HD researcher and currently a professor at the University of California-Irvine School of Medicine. Dr. Wheelock is a beloved and well-respected neurologist at HDSA's Center of Excellence at the University of California-Davis.

Special thanks to **Dr. Jang-Ho Cha**, **Dr. Michelle Gray** and **Arvind Shreedharan** who have completed their terms on HDSA's National Board of Trustees. Each will remain 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 20,000<sup>th</sup> participant was recruited at the study site in Leuven, Belgium. This extraordinary milestone was made possible thanks to the efforts of the sites and the families. For more info about Enroll-HD please visit [www.enroll-hd.org](http://www.enroll-hd.org)

**#MyCauseMyCleats  
with NFL Superstar Aaron Donald**



The NFL campaign #MyCauseMyCleats gives players the opportunity to support their favorite charities by wearing custom cleats.

Aaron Donald from the L.A. Rams wore cleats featuring the HDSA logo to support families affected by Huntington's disease.

Photo: Mark J. Rebilas, USA TODAY Sports



From left to right: Daniel Pirrello; Caralyn Duke with top fundraiser Maggie Kiselick; and Ally Bejma

**HDSA's New York City Marathon Team**

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

**2018 HDSA NYC MARATHON TEAM ROSTER:**

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



**Inside the O'Briens  
Coming to the Big Screen**

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

**Here's The Deal**

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



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

**Freeze HD Event Raises Nearly \$200,000**

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

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



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



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

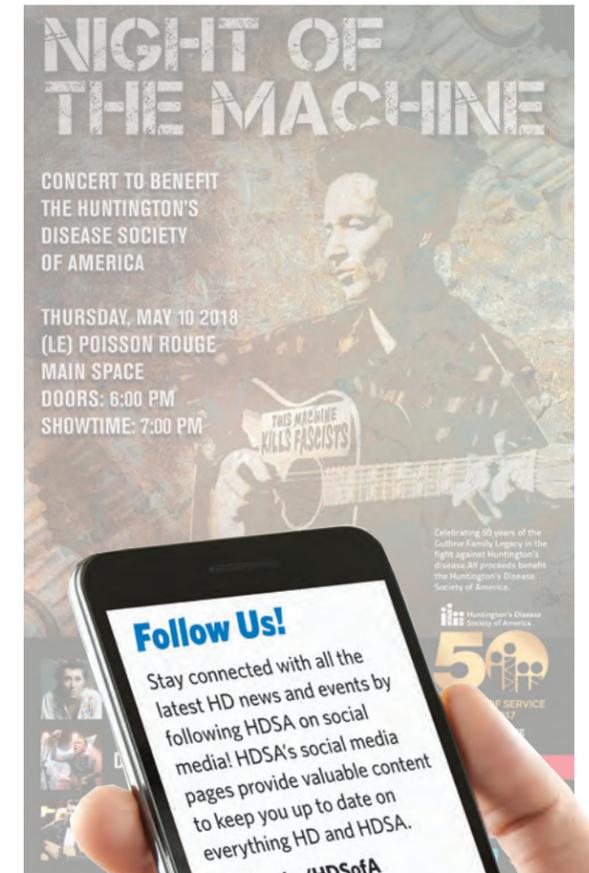
**May is HD Awareness Month,  
So #LetsTalkAboutHD!**

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

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

**This Week In HD Research**

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



**Follow Us!**

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

- Facebook: /HDSofA
- Twitter: @HDSA
- Instagram: HDSANational
- YouTube: HDSA.org/youtube



**HDSA's 33<sup>rd</sup> Annual Convention**  
 June 7-9, 2018 / Los Angeles, CA

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

"On behalf of the HDSA Board of Trustees, staff and volunteers I would like to thank everyone who supported and attended the 33<sup>rd</sup> Annual HDSA

1,046  
TOTAL  
ATTENDEES

52.3%  
WERE FIRST-TIME  
ATTENDEES

96  
N.Y.A. MEMBERS  
ATTENDED

52  
SCHOLARSHIPS  
WERE GRANTED

100  
EXHIBITORS  
PARTICIPATED

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 carnival-themed Welcome Reception. Guests were greeted by a surprise video greeting from actress **Bryce Dallas Howard** who donated four tickets to the LA premiere of her latest film, **Jurassic World: Fallen Kingdom**.



The excitement did not stop there, Bryce then introduced an HDSA Convention exclusive sneak peek and extended trailer of the film.



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.

On 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. Anne Smith, Dr. Holly Kordasiewicz, Dr. Robert Pacifici, Dr. Doug Macdonald, Dr. Ed Wild, Dr. Blair Leavitt, Erik Lundgren, Dr. George Yohrling** and HD family advocate **Amy Fedele**.

**Dr. Jeff Carroll** and **Dr. Wild** from **HDBuzz.net** also delivered an informative and highly entertaining update on HD research.

Saturday night's **Awards Dinner and Gala** closed out this memorable Convention with amazing food, entertainment and dancing. HDSA National Convention Awards were presented on Saturday evening (see list at right). HDSA also recognized both the **Guthrie** and **Wexler Families** in a special tribute that was presented by Anna Canoni.



For the 20th year, **Marie Nemec** and **Charlotte Reicks** led a team of dedicated advocates who once again rode bicycles to the HDSA Convention while raising money for HDSA. To date, **Bike For The Cure** has raised more than \$730,000!

The 33<sup>rd</sup> Annual Huntington's Disease Society of America Convention was made possible by the generous support of its sponsors: **Archcare, BioTek, reMedys, Broda, Enroll-HD, Genentech, Huntington Study Group, Ionis Pharmaceuticals, Lundbeck, Mass Mutual, PTC Therapeutics, Tagi Pharma, Teva Pharmaceuticals, uniQure, Vaccinex, Voyager** and **WAVE Life Sciences**.



**HDSA National Convention Awards**

**Woody Guthrie Advocacy Award**  
 Frances Saldana

**HDSA Excellence In Care Award**  
 Kaiser Permanente Northern California

**HDSA Marjorie Guthrie Award**  
 The Johnston Family

**HDSA Research Award**  
 Dr. James F. Gusella

**HDSA Person of the Year**  
 Jeannette Garcia

**Affiliate of the Year**  
 Central Maryland Affiliate

**Chapter of the Year**  
 Greater New York Chapter

# HDSA 2018 Regional Event 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!

Special thanks to our National Events Sponsor



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

## PACIFIC REGION



**Celebration of Hope Gala**  
A World of Sports — According to Joe Buck  
San Diego Chapter  
\$380,000

**San Diego Team Hope Walk**  
San Diego Chapter  
\$85,000

**San Diego Shoot To Cure HD**  
San Diego Chapter  
\$79,000

## SOUTH CENTRAL REGION

**Heroes vs. Villains 5K Walk/Run**  
Rocky Mountain Chapter  
\$42,700

**4th Annual Austin, Texas Team Hope Walk**  
Regional Event  
\$28,267

**South Houston "Sabedra" Team Hope Walk**  
Greater Houston Area Affiliate  
\$21,000



## UPPER MIDWEST REGION

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



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

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



## GREAT LAKES REGION



**9th Annual Northeast Ohio Chapter Celebration of Hope**  
Northeast Ohio Chapter  
\$181,870

**Illinois Team Hope Walk**  
Illinois Chapter  
\$109,500

**Liberty, MO Team Hope Walk**  
Regional Event  
\$86,375

## NEW YORK / NEW JERSEY REGION

**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



## MID-ATLANTIC REGION

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

**Fast Track for a Cure**  
Western Pennsylvania Chapter  
\$20,200

**Philadelphia Team Hope Walk**  
Eastern Pennsylvania Chapter  
\$18,300

## SOUTHEAST REGION

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

**27th Annual Cure HD Triathlon**  
South Florida Chapter  
\$59,442

**Atlanta Team Hope Walk**  
Georgia Chapter  
\$43,064

## NEW ENGLAND REGION



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

**Boston Team Hope Walk**  
Massachusetts Chapter  
\$43,268

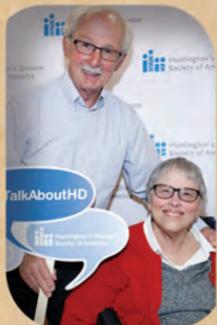
**Tewksbury Team Hope Walk**  
Massachusetts Chapter Event  
\$33,000





Family is  
*Everything*

 Huntington's Disease Society of America



# Research Report

BY GEORGE YOHLING, Ph.D.

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.

**Genentech**  
A Member of the Roche Group

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 19<sup>th</sup>, 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



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

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!



**GEORGE YOHLING, Ph.D.** is HDSA's Senior Director of Mission and Scientific Affairs

## Expected 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, Pasadena**  
Arcadia Neurology Center

**CALIFORNIA, San Diego**  
University of California, San Diego

**COLORADO, Englewood**  
Rocky Mountain Movement Disorders Center

**FLORIDA, Tampa**  
University of South Florida

**ILLINOIS, Chicago**  
Northwestern University

**MARYLAND, Baltimore**  
John 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

**WASHINGTON, Kirkland**  
Evergreen Health

**WASHINGTON, D.C.**  
Georgetown University

# Advocacy Report

BY JENNIFER SIMPSON, LCSW

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

**Health Council** to fight against measures that would have negatively impacted families with Huntington's disease. We fought against cuts to Medicare and Medicaid, rollbacks of protections for individuals with pre-existing conditions, the creation of high-risk pools which would have raised healthcare costs for folks with complex and chronic diseases like HD,

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



In 2018 we also said goodbye to our long-time Washington insider **Jason Gromley**. Jason worked with HDSA and the HD community for 7 ½ years advancing important legislation and regulatory

initiatives to streamline access to Social Security Disability, Medicare and helped us forge important relationships within the FDA to help them better understand the needs of HD patients and their families. Although we will 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.



**JENNIFER SIMPSON, LCSW** is HDSA's Senior Manager of Advocacy and Youth Programs.

# Education Report

BY DEBRA LOVECKY, MS

2018 continued to be an outstanding year for HDSA's lay and professional educational efforts. In the area of lay education, HDSA was able to support 49 field based educational days which included guest speakers at support groups as well as full and half day programs.

In addition to outstanding programming in the areas of both care and research, every attendee received an HDSA information packet that contained valuable materials about support groups, HDSA Centers of Excellence and chapters/affiliates in their region. More than 2,700 HD family members and healthcare professionals attended these events with seven multi-track state conventions attracting more than 100 family members to each. HDSA thanks **Teva** for their generous unrestricted educational grant which made these events possible.



In June, more than 1,000 HD family members travelled to Los Angeles, CA to attend **HDSA's 33<sup>rd</sup> Annual Convention** which honored and commemorated HDSA's 50 years of service to



the HD community. In an inspiring keynote address on Friday, **Anna Canoni**, Woody Guthrie's granddaughter, 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, HDSA also streamed and recorded

ten workshops that can be viewed online at: **HDSA.org/convention**

In the area of professional education, HDSA travelled to Salt Lake City UT to conduct a day long training session on HD as part of the **American Occupational Therapy Association (AOTA)** pre-conference institute. Speakers included **Sandra Kostyk, M.D., Ph.D.**, HDSA Center of Excellence at the Ohio State University; **Lisa Warren, OTR/L**, HDSA Center of Excellence at the University of Florida; **Jan Rowe, OTD, OTR/L**, University of Alabama, Birmingham; **K. Michelle Knewstep-Watkins, OTD, OTR/L**, Mary Baldwin University; **Theresa Berner, MOT, OTR/L**, HDSA Center of Excellence at Ohio State University; and **Anne Leserman, LCSW** from HDSA.

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 HDSA's goal of increasing access to knowledgeable community based occupational therapists. HDSA will be partnering with AOTA in 2019 to launch a new four-part course which will run for three years.



**Medscape**

In late 2017, HDSA partnered with **Medscape** and the **University of Alabama School of Medicine** to produce an online three-part accredited continuing education course on HD for community based primary care providers,

At Left: Segment from the Module 1 online course, 'HD in the 21<sup>st</sup> Century' with Drs. Victor Sung and Erin Furr-Stimming.



neurologists and psychiatrists that featured ten of our HDSA Centers of Excellence directors sharing their knowledge and HD expertise in the areas of diagnosis, treatment options and the benefits of a multidisciplinary team approach to care.

Over the past twelve months, more than 4,600 medical professionals have taken one or more of the modules with more than 2,100 completing **Module 1 (HD in the 21<sup>st</sup> Century** with **Victor Sung, M.D.** and **Erin Furr-Stimming, M.D.**), almost 1,400 completing **Module 2 (Best Practices in HD: Role of the Multidisciplinary Team** with **Drs. Sandra Kostyk, Madaline Harrison, Valerie Suski, Daniel Claassen, and Claudia Testa**) and almost 1,500 completing **Module 3 (Best Practices in the Clinical Management of HD** with **Drs. Sam Frank, Jee Bang and Danny Bega**). The course was made possible through an unrestricted educational grant from Teva. HDSA is proud to have been a partner with UAB and Medscape and to have had the opportunity to feature so many of our outstanding HDSA Center of Excellence directors as part of the program.



**DEBRA LOVECKY, MS** is HDSA's Director of Educational Programs.

# Support & Services Report

BY ANNE LESERMAN, LCSW

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

continues to person a **Helpline (800-345-HDSA)** for families and professionals and refers to the chapter and regional social workers who respond to thousands of requests for information about HD, provide supportive counseling, answer questions about genetic testing, long term care placement, disability and referrals to local resources. Social workers also interact with professionals in their communities doing presentations to medical students, genetic counseling students, behavioral

health students, law enforcement personnel, 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 that are available in 45 states. Our on-line support groups continue to grow for caregivers, those at risk for HD, those early in the course of their illness and parents caring for children with HD. 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 are also offered for free through **AmWell**, a telehealth program. Many continue to take advantage of free counseling sessions to get assistance from mental health professionals knowledgeable about HD.



To find services in your area visit us online at: [HDSA.org/locateresources](https://www.hdsa.org/locateresources)



**ANNE LESERMAN, LCSW** is HDSA's Assistant Director of Community Services.

# Youth Program Report

BY JENNIFER SIMPSON, LCSW

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



**JENNIFER SIMPSON, LCSW** is HDSA's Senior Manager of Advocacy and Youth Programs.



# HDSA Leadership

## HDSA Board of Trustees

E.J. Garner, *Chair*  
Victor Sung, M.D., *Chair-Elect*  
Daniel S. Vandivort, *Treasurer*  
Jennifer Leyton, *Secretary*  
Arik Johnson, Psy.D., *Past-Chair*  
Kamran Alam  
Dan Brennan  
Stacy Coen  
Jenne Coler-Dark  
Gerald Francese, Esq.  
Donald Higgins, M.D.  
Bill Klein  
Teresea Srajer  
Leslie Thompson, Ph.D.  
Vicky Wheelock, M.D.

## HDSA Staff Leadership

Louise Vetter, *President & Chief Executive Officer*  
George Yohrling, Ph.D., *Senior Director of Mission & Scientific Affairs*  
Christopher Cosentino, *Director of Marketing & Communications*  
Nancy Rhodes, *Director of Field Development & Operations*  
Jamison Skala, *Director of Development*

keep  
moving  
forward



## 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.

Please  
join us!



**HDSA 34 BOSTON**  
34<sup>TH</sup> ANNUAL HDSA CONVENTION  
JUNE 27-29, 2019

## SAVE THE DATE!

Join us for the 34<sup>th</sup> Annual HDSA Convention  
in historic Boston at the Marriott Boston Copley Place.

**JUNE 27-29, 2019, BOSTON, MA**

Register today at [HDSA.org/convention](http://HDSA.org/convention)





505 Eighth Avenue  
Suite 902  
New York, NY 10018

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

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



© 2019 Huntington's Disease Society of America  
All Rights Reserved.