



# HDSA 2019 YEAR IN REVIEW





## TABLE OF CONTENTS

<b>PRESIDENT &amp; CEO MESSAGE</b>	1
<b>2019 HIGHLIGHTS</b>	2
<b>2019 REGIONAL EVENT HIGHLIGHTS</b>	14
<b>RESEARCH FUNDING PROGRAMS</b>	16
<b>2019 MISSION REPORTS</b>	20
Research	22
Advocacy	23
Education	24
Youth Programs Report	25
Support & Services Report	26
Disability Programs Report	27
<b>35<sup>TH</sup> ANNUAL HDSA CONVENTION</b>	28
<b>MISSION &amp; VISION STATEMENTS</b>	<i>Inside Back Cover</i>
<b>BOARD OF TRUSTEES</b>	<i>Inside Back Cover</i>
<b>STAFF LEADERSHIP</b>	<i>Inside Back Cover</i>

# HDSA 2019 YEAR IN REVIEW

Dear Friends of HDSA,

Are we where we want to be? **NOT YET.** Are we getting closer? **YES!** Putting all the great advancements in research aside, it is important to be reminded that there are still thousands of families impacted by Huntington's disease that are in dire need of support right now. Although we are excited to report on promising research news — there is still no treatment for HD and our work is not done. In 2019 we worked hard to expand these services to provide world-class support to families from coast to coast.

**This year we expanded our Centers of Excellence program to 47 facilities and 6 clinical sites across America where more families can receive expert care.** With new Centers in California, Illinois, New York and North Dakota, HDSA now offers care locations in 31 States plus the District of Columbia. This year, HDSA awarded a total of \$1.4 million to the Centers of Excellence program, an almost eleven percent increase in funding from 2018.

**The Huntington's Disease Society of America also added new staff positions to play integral roles in supporting HD families.** In June, we welcomed **Allison Bartlett, Esq.** to serve as HDSA's Manager of Disability Programs. Allison has been able to assist countless families through the complex disability process as well as host **Disability Chats** to provide valuable insight into social security and what is needed for approval.

**We know youth are a powerful voice in the fight against HD.**

Young adults and children from HD families continue to be wonderful advocates and their passion is never overlooked. However, we knew we needed to create more support programs for youth impacted by HD which is why we welcomed, not one, but two youth social workers to the HDSA team. Thanks to the **Griffin Foundation, Katie Dykman, LISW** and **Jessica Marsolek, LGSW** are professionals trained to serve young people and respond to the unique needs of children, teens and young adults impacted by HD.

**With more hands on deck, we are able to improve our tremendous support programs even more,** such as HDSA's telehealth program, online support groups, HD Trialfinder and helpline — **All free. All the time.**

**HDSA is on the forefront of supporting promising HD research.**

In 2019, we funded more HD science than ever before including more than \$1.4 million in direct grants to scientists. We also continued to cultivate strong relationships with leading bio-pharmaceutical partners.

As our founder Marjorie Guthrie said, "We must continue to search for HD families everywhere." Through strategic outreach and engagement efforts, HDSA has generated more awareness than ever before. We are getting more influencers involved who are using their platforms to bring HD families together and let them know how to find the help they need.

**Once again, our work is not done, but because of you we are able to let HD know — we are never giving up this fight until we are in a world free of Huntington's disease.**

Sincerely,

**Louise Vetter**  
President & Chief Executive Officer



# 2019 HIGHLIGHTS

## HDSA CENTERS OF EXCELLENCE GROW TO 47 SITES ACROSS THE U.S.

In 2019 HDSA announced that forty-seven outstanding Huntington's disease care facilities with six satellite sites were awarded the designation of HDSA Centers of Excellence.

This was an increase from 43 in 2018, and from just 20 in 2015. The four new 2019 Centers of Excellence are: OSF HealthCare Illinois Neurological Institute (Peoria IL), Sanford Health, (Fargo, North Dakota), University of Buffalo (New York) and University of California, Irvine. 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.

The strategic expansion of the Center of Excellence program allows HDSA to increase access to expert HD clinical care and clinical trial opportunities to more families across the United States. With new Centers in California, Illinois, New York and North Dakota, HDSA now offers care locations in 31 states plus the District

of Columbia. **This year,**

**HDSA awarded a total of \$1,418,684 to the Centers of Excellence program, an almost eleven percent increase in funding from last year.**



OSF HealthCare Illinois Neurological Institute (Peoria, Illinois)



Sanford Health, (Fargo, North Dakota)



HDCARE Clinic, Gottschalk Medical Plaza, University of California, Irvine



UBMD Neurology, University of Buffalo (New York)



"HDSA is deeply committed to helping families affected by Huntington's disease have access to experienced and family-focused care," said **Louise Vetter**, HDSA's President & Chief Executive Officer. "The recognition of new Centers of Excellence means that more families will benefit from comprehensive care and the life-changing treatment and research opportunities that drive us forward towards finding a cure for this disease."

The HDSA Centers of Excellence provide an expert

team approach to Huntington's disease care and research. Patients benefit from expert neurologists, psychiatrists, social workers, 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 to all clinics in the United States who share HDSA's commitment to high-quality, comprehensive care and access to clinical research.

## HDSA AWARDS INAUGURAL CLINICAL RESEARCH PILOT GRANTS TO FOUR CENTERS OF EXCELLENCE

In December, HDSA awarded four grants under a new research initiative, the **HDSA Center of Excellence Clinical Research Pilot Program**. These grants, totaling \$50,000, represent HDSA's patient-centric research focus by fostering novel clinical research projects within the HDSA Center of Excellence network.

These pilot projects will unite scientists with patients through the direct participation of HD families in clinical research. The funding provides

an opportunity for HDSA Center of Excellence directors and staff to get a new research ideas off the ground.

"I am excited about this year's recipients because their innovative proposals could positively impact the way HD care and counseling are delivered, how symptoms are treated and how disease progression is monitored," said **George Yohrling, PhD**, Chief Scientific Officer and Chief Mission Officer at HDSA.

Applications for this grant mechanism were open to all 47 HDSA Centers of Excellence and their six partner sites. Ultimately, grants were awarded to four research teams on the following projects:

**HDSA Center of Excellence Partner Site at Oregon Health & Science University, Dr. Amie Hiller**  
*Measuring Cortisol Levels in Persons with Huntington's Disease*

**HDSA Center of Excellence at Rush University Medical Center, Dr. Deborah Hall**  
*Optimization of Tele-Genetic Counseling for Huntington's Disease*

**HDSA Center of Excellence at University of Texas Health Science Center, Dr. Erin Furr-Stimming**  
*Melatonin for HD Gene Carriers with HD Related Sleep Disturbance*

**HDSA Center of Excellence at the University of Virginia, Dr. Madaline Harrison**  
*Training in Primary Palliative Care for Huntington's Disease*

"Our HDSA Centers of Excellence are at the epicenter in the search for better HD care and treatments. HDSA is pleased to support these pilot programs in the confidence that our investment today will provide a brighter future for all HD families," said **Louise Vetter**, HDSA's President and Chief Executive Officer.



## THE STARS SHINE AT FREEZE HD GALA

On Saturday, September 28<sup>th</sup>, four hundred guests attended the **5<sup>th</sup> Annual Freeze HD** at Avalon Hollywood where **more than \$420,000 was raised to support HDSA's fight against Huntington's disease**. This star-studded event was hosted by actor **Lamorne Morris** and honored **Kelsey and Scott Porter**. Some notable guests included **Seth Green, Topher Grace, Jason Ritter, Katherine McNamara, Marianna Palka, Kate Miner, Rachel Bilson, Wilson Bethel, Jaime King** and **Allie LaForce**. The event featured incredible live performances from **Brian Logan Dales** and **The Dales Hotel**, **Tyson Ritter** from **The All-American Rejects**, **DJ Skee, DJ Prophet, Emma Hutton, Leslie Powell** and **Scott Porter**. Actor **Will Ferrell** donated

\$10,000 to support this wonderful night!

"The 5<sup>th</sup> Annual Freeze HD was the largest fundraising event ever hosted to support our organization and we couldn't have done it without our incredible honorees, **Scott and Kelsey Porter**, sponsors, event committee and everyone who attended as well as bid on the amazing auction items," said **Louise Vetter**, HDSA's President and Chief Executive Officer. "Thank you everyone — this was truly a showcase of the extraordinary strength of the HD community."

The incredible auction included exciting trips, signed TV/movie & sports memorabilia, once-in-a-lifetime experiences, exclusive tickets,

gaming equipment and so much more! Freeze HD was supported by a wonderful event committee that included **Rachel McAdams, Jason Ritter, Jaime King, Marianna Palka, Simon Helberg, Bryce Dallas Howard, Kenneth and Diane Mayfield, Blake and Jenne Coler-Dark, Brian Logan Dales, Matt and Courtney Hamilton, Jamie Linden, Justin and Kate Miner, Elliott and Tracy Owen, Carly Ritter, Nancy Morgan Ritter, Tyler and Lelia Ritter, Jason Ziven, Angelique Cabral, Jaylen Moore** and **Britt Logan, Gentile Kosed, Kyle Newman, Adam Seid, Jessica Cain, Emily and Jamie Rodgers** and **Alana Yankowitz**.

MORE THAN  
**\$420,000**  
WAS RAISED  
AT THE 5<sup>TH</sup>  
ANNUAL  
FREEZE HD  
GALA

## Special Thanks To Our Freeze HD Gala Sponsors

### GOLD SPONSORS

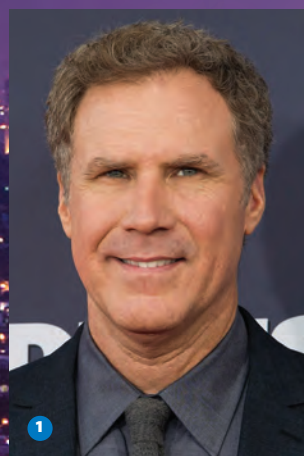
- Genentech
- The Ferrell-Paulin Family Foundation

### SILVER SPONSORS

- Bel Air Internet
- Cambium Networks
- Keyes Real Estate
- Marron Foods
- Wave Life Sciences
- Winncom Technologies

### BRONZE SPONSORS

- After Hours Theatre Company
- Amberlee Colson
- California Horizon Pool & Spa
- Educated Nannies
- Fake Empire
- Ferrandino & Son, Inc.
- Freemark Financial LLP
- Robert Kirkman
- Rumble Riot Pictures
- Temple Hill Entertainment
- The MBS Group
- The O.C.D. Experience
- Wilson Bethel
- William Morris Endeavor



1. Will Ferrell 2. Ashley Hinshaw and Topher Grace 3. Freeze HD Introduction 4. Jason Ritter 5. Scott Porter, Jaime King, Rachel Bilson and Wilson Bethel share a playful moment 6. Kate Miner and Briana Lane 7. Todd Grinnell 8. Jaylen Moore strikes a pose 9. Marianna Palka and Kate Miner share a laugh 10. Tyson Ritter 11. HDSA President & C.E.O., Louise Vetter with Freeze HD Gala honorees, Scott and Kelsey Porter 12. Freeze HD Gala host, Lamorne Morris 13. Jaime King 14. Rachel Bilson 15. Katherine McNamara 16. Seth Green and Clare Grant 17. Brian Logan Dales performs 18. Rachel McAdams 19. Freeze HD Gala honorees, Scott and Kelsey Porter address the guests



## HDSA FILMS DEBUT

In 2019, HDSA produced three powerful short films — *Carol & Richard: A Love Story*, *The Hodgsons*, and *The Vaughns*. All were directed by **Rae Maxwell**. The films are featured on HDSA's YouTube Channel and each has received thousands of views.

*At right, a scene from The Hodgsons, produced by HDSA Films.*



HDSA Films

## 'HERE'S THE DEAL' VIDEO SERIES

HDSA's **Jennifer Simpson, LCSW** continues to host *Here's The Deal*, an online video series that features insightful conversations with members of the HD community. This past year's topics included *Isolation, Family Planning, Caregiving While Positive* and *Parenting a Child With JHD*. Visit HDSA's YouTube Channel to watch the entire *Here's The Deal* series.



## SEPTEMBER 18: HDSA'S FOUNDER'S DAY OF GIVING



On **September 18th**, HDSA launched **The Founder's Day of Giving** to pay tribute to our founder, Marjorie Guthrie. It was on September 18, 1967 our organization was founded. In just its first year, Founder's Day of Giving raised more than \$10,000 to support the first-time attendee **HDSA Convention Scholarship Program**. **Thank you!**

## CELEBRITIES RAISE HD AWARENESS

**Seth Green, Jason Ritter, Marianna Palka, Kate Miner, Jaime King & Rachel Bilson, Nyambi Nyambi, Wilson Bethel, Scott Michael Campbell**

6

## 'ALL IN TO END HD' CASINO NIGHT WITH GUILLERMO

The *'All In To End HD' Casino Night* took place on Saturday, June 1 at the Continental Club in downtown Los Angeles. The evening featured a speakeasy venue setting, live music from jazz singer **Andrea Miller**, various gaming tables and an appearance from emcee **Guillermo** from *Jimmy Kimmel Live!* The event successfully brought in 125 guests and raised \$35,000 for our HD community — all while engaging new committee members, potential sponsors and local influencers for next year.



Jazz singer **Andrea Miller** and **Guillermo Rodriguez** from ABC's *Jimmy Kimmel Live!*

and **Rachel Nichols** are among many more celebrities who continue to generate much-needed HD awareness through **#LetsTalkAboutHD** public service announcements.

## GILLETTE TREO™ RECEIVES POSITIVE REVIEWS FROM HD FAMILIES

This year, HDSA partnered with **Gillette** to test a new product with HD caregivers. The **Gillette TREO™** razor features a built-in shave gel and is the first razor specifically designed to shave someone else. Designed with caregivers, for caregivers, TREO has a safety comb that helps protect the skin and prevent clogging, an ergonomic handle for great comfort and control, and a special non-foaming gel that hydrates the hair with no water required.



HDSA looks to continue this great partnership to bring useful products to HD families.

*You can learn more about the Gillette TREO razor by visiting [Gillette.com/TREO](http://Gillette.com/TREO).*

## STARTING A FAMILY AMID HD CONCERNS DISCUSSED ON NBC'S THE TODAY SHOW

HD facts and statistics provided by HDSA were featured on *The Today Show* in February when our dear friends, TNT basketball reporter **Allie LaForce** and husband **Joe Smith** of the Houston Astros appeared for an exclusive interview. The couple shared their concerns about starting a family since Joe's mother suffers from HD. **Dr. Erin E. Furr-Stimming**, a neurologist from the University of Texas HDSA Center of Excellence, whose team was recently awarded a Clinical Research Pilot Grant by HDSA, also appeared.



TNT's **Allie LaForce** and the Houston Astros' **Joe Smith** appeared on NBC's *The Today Show*.



*Charlotte Reicks (left) and Marie Nemec*

## 'BIKE FOR THE CURE' FEATURED IN BICYCLING MAGAZINE

After 20 years and 20,000 miles, *Bike for the Cure* was featured in *Bicycling* magazine. Over the past 20 years, **Charlotte Reicks** age 83, and **Marie Nemec**, 74, rode more than 20,000 miles for Huntington's Disease Society of America. They crossed 48 of the 50 contiguous states, connecting people and communities while growing their mailing list — their main source of donations. As of December, 2019 they have raised over \$743,000 to fight HD!

7

## COMEDIAN ROD MAN HOSTS HD FUNDRAISER — 'MAIN STREET LIVE'

Comedian **Rod Man** who comes from an HD family, hosted his annual talent show — *Main Street Live* — in Georgia to raise funds and awareness for HD. Rod has appeared on NBC's *Last Comic Standing*. This year his charitable event raised more than \$3,000 to support HDSA's mission.

*Comedian, Rod Man*



## HDSA'S 34<sup>TH</sup> ANNUAL CONVENTION IN BOSTON SETS ATTENDANCE RECORD

The 34<sup>th</sup> Annual Huntington's Disease Society of America (HDSA) Convention was held in Boston, Massachusetts on June 27<sup>th</sup>-29<sup>th</sup> at the Boston Marriott Copley Place. With 1,225 guests, the Convention set a new attendance record breaking the previous record (1,046) in Los Angeles, California held last year. The 35<sup>th</sup> Annual HDSA Convention will be held in New Orleans, Louisiana on June 4<sup>th</sup>-6<sup>th</sup>, 2020.

"The 34<sup>th</sup> Annual HDSA Convention not only set a new attendance record, but it also confirmed the momentum of the HD community that is actively working to improve the lives of everyone

affected by Huntington's disease," said **Louise Vetter**, HDSA's President and CEO. "With the incredible advancements in HD research and care, HD families are engaged and invigorated to go out and do something. We could not put an event of this magnitude together without the help of our amazing sponsors who we are grateful to call our friends in the fight against HD."

The festivities kicked-off on Thursday with the **Team Hope Walk** through the historic streets of

Boston, which led to the carnival-themed Welcome Reception. During the Opening Ceremony on Friday morning, **Dr. Jang-Ho Cha**, **Dr. Marcy McDonald** and **Cheryl Sullivan-Stavelly** led a moving panel discussing the dynamic relationship between research and HD families.

Friday afternoon featured the Cheers-themed **VolunCheers Luncheon** where the Society cheered the extraordinary efforts of the HDSA volunteers. Friday night's **HDSA National Youth Alliance Talent Show** raised more than \$35,000 for the **NYA Scholarship Fund** which sends children and young adults impacted by HD to the HDSA Convention each year.

The education tracks were jam-packed with workshops from world-class speakers, including Nobel Laureate **Dr. Craig Mello** who delivered the Keynote Address during Saturday's **Research Forum**. Also during the Research Forum, **Dr. Ed Wild** and **Dr. Jeff Carroll** from HDBuzz gave an in-depth and entertaining update on HD research and promising clinical trials entitled "**HD Avengers — Endgame?**".

The Convention culminated with Saturday night's elegant Gala Reception where HDSA honored individuals and groups for outstanding achievements with the **HDSA 2019 National Awards** (see list at right).

As is tradition, the Convention closed with the emotional candle lighting ceremony paying tribute to the entire HD community.



### HDSA 2019 NATIONAL AWARDS

**Woody Guthrie Advocacy Award**  
Seth Rotberg and  
Therese Crutcher-Marin

**HDSA Youth Award**  
Hallie Kile

**Researchers of the Year**  
Dr. Darren Monckton and  
Dr. Vanessa Wheeler

**HDSA Chapter of the Year**  
HDSA New Jersey Chapter

**HDSA Affiliate of the Year**  
HDSA Connecticut Affiliate

**Inaugural Long-Term Care Award**  
Sitrin Health Care Center

**HDSA Excellence in Care Award**  
Dr. Samuel Frank

**Marjorie Guthrie Award**  
Patricia McLane and  
Morgan McLane

**HDSA Person of the Year**  
Alexandra Boothby

*E.J. Garner, HDSA Board of Directors Chair (l.) and Louise Vetter, HDSA President & CEO (r.) present Alexandra Boothby HDSA's 2019 Person of the Year Award.*

The 34<sup>th</sup> Annual HDSA Convention was made possible by the generous support of all its sponsors:

#### PRESENTING SPONSOR

- Genentech
- Teva Pharmaceuticals

#### PLATINUM SPONSOR

- Lundbeck

#### GOLD NONPROFIT SPONSOR

- CHDI Foundation / Enroll-HD

#### SILVER SPONSORS

- Ionis
- uniQure

#### BRONZE SPONSORS

- MassMutual SpecialCare
- Voyager
- Wave Life Sciences

#### FRIEND SPONSORS

- Archcare
- BioTek reMEDys
- Broda
- Next Step Healthcare
- PTC Therapeutics
- Sanofi
- Spark Therapeutics
- UMass Medical School
- Vaccinex
- WilmerHale



## HDSA ADDS THREE TRUSTEES TO NATIONAL BOARD

The Huntington's Disease Society of America is excited to welcome three new members to the Society's national Board of Trustees.

**Wendy Erier** is the Vice President of STAR and Patient Insights and Advocacy at Alexion Pharmaceuticals where she is responsible for building an enterprise holistic solution model to gather and incorporate patient insights throughout the drug development and commercialization processes. She leads the Global Patient Advocacy function and has responsibility the advocacy team. Previously, Ms. Erier was on the executive leadership team at Wave Life Sciences where she led Patient Advocacy and Commercial. Wendy graduated from Miami University and earned her MBA from St. Joseph's University.



Wendy Erier

**Jay Hughes** is MGIC's Executive Vice President of Sales and Business Development. He began his career with MGIC in 1987 as an Account Executive in the northern Virginia market. After moving to California in 1998 to assume the role of Sales Manager, Jay was promoted to Vice President-Managing Director in 2001 covering MGIC's Pacific Region. In 2014, Jay accepted the position of Senior Vice President, Sales and Business Development and relocated to Milwaukee, Wisconsin. In his current role as Executive Vice President of Sales and Business Development, Jay is responsible for MGIC's five regions, our National Account relationships and Marketing. He holds a Bachelor of Science degree in Finance from the Villanova School of Business.



Jay Hughes



Jonathan Klein

**Jonathan Klein** is Chair of the Mergers and Acquisitions Group at DLA Piper in New York City. He concentrates his practice in the areas of mergers and acquisitions, private equity, corporate finance, securities matters and restructuring for both domestic and international clients. Jonathan has represented US and foreign clients in connection with cross-border acquisitions, divestitures, joint ventures, private financings, loan restructurings and workouts and general corporate matters. Jonathan received his J.D. from Georgetown University Law Center where he graduated cum laude and his B.S. from Cornell University.

"We are thrilled to welcome Wendy, Jay and Jonathan to HDSA's Board of Trustees," said **Louise Vetter**, HDSA's President & Chief Executive Officer. "Their diverse skills and experiences will help contribute to the Society's ability to achieve its mission and support families affected by HD."

In other Board-related news, **Kamran Alam** was appointed Treasurer and **Jenne Coler-Dark** will assume the role of Secretary. **Bill Klein** and **Jennifer Leyton** have successfully fulfilled their six-year term as integral members of HDSA's Board of Trustees.

We are grateful for the exceptional volunteer leadership that guides our mission work!

## HDSA'S NYC MARATHON TEAM RAISES MORE THAN \$133,000

HDSA's 2019 New York City Marathon team featured twenty-five runners from twenty different States across the US all willing to take on 26.2 miles to support the fight against HD. **To date, the team raised more than \$133,000 finishing in the top 18 among all NYC Marathon Charity Partners!**



Clockwise from left: Craig Robinson, Samantha Cox, Kari Baker, and Janine Lind Trembicki

Special thanks to the accounting firm **EisnerAmper** for being the team's Presenting Sponsor. The team's fastest runner was **Craig Robinson** who finished with an impressive time of 2:34:55 — good enough for 118th overall! The team's top fundraiser was **Kari Baker** from Florida who raised more than \$11,000!

### HDSA's 2019 New York City Marathon Team:

**Mark Adler, Kari Baker, Jennifer Bandley, Madeline Bolton, Michael Boyle, Aly Boyle, Molly Corse, Samantha Cox, Carlos Fonts, Jonathan Harrison, Emily Lefler, Janine Lind Trembicki, Paula Lintz, Jessica Marsolek, Erin Milek, Jessica Parker, Alycia Patty, Carolyn Plaza, Ricardo Puente, Craig Robinson, Amber Rutledge, Michael Shea, Rod Thompson, Kristen Westdorp and Sara Witzl.**

### COUNTRY STAR CHRIS STAPLETON SUPPORTS HDSA

After being introduced to HDSA's rich musical history and incredible mission, singer-songwriter **Chris Stapleton** donated \$5,000 to improve the lives of people with HD and their families.



### NEW LOOK, NEW RESOURCES AT HDSA.ORG

In January HDSA released a new website design with improved navigation, Google Translate and other exciting new features found at **HDSA.org!**

### 'THIS WEEK IN HD RESEARCH' BLOG

HDSA's **Leora Fox, PhD** provides weekly updates in the **This Week In HD Research** blog. Dr. Fox keeps you up-to-date on HDSA research activities, recently published work about Huntington's disease, historical moments in HD research and more. **Follow the blog at HDSA.org/blog**



### FOLLOW US! HDSA.ORG

facebook.org/HDSofA @HDSA  
HDSANational HDSA.org/Youtube



## HD LEGACY — THE GIFT TO FUTURE GENERATIONS

In response to a growing need to study exactly what Huntington's disease (HD) does to the human brain, **HDSA** and **CHDI Foundation** announced a new collaboration in 2019 called **HD LEGACY** to support brain and other organ donations from families affected by HD who would like to make a vital contribution to research.

This new program encourages the donation of brain and other tissues from HD gene-expansion carriers, at-risk individuals, and healthy family controls. The **Harvard Brain Tissue Resource Center (HBTRC)** will assist interested families throughout the process, and families will bear no costs associated with the donation.

"The decision to donate one's body to science is an amazingly selfless act," said **Louise Vetter**, President and CEO at HDSA. "Participating in HD LEGACY is truly a gift for future generations. The brains and other organs donated through this program will leave a 'legacy' of hope, inspiring new knowledge that will someday stop HD in its tracks."

"Science still has a quite rudimentary understanding of how the human brain works," said **Robi Blumenstein**, President of CHDI Management, Inc. "Researchers need more brain donations from HD-affected individuals to better understand how HD affects the human brain, what happens to the different cell types and circuits that make up the brain over time. HD LEGACY will give us new insight into how to intervene therapeutically."



## INSPIRATIONAL RUNNER SUPPORTING HDSA HIGHLIGHTED IN *RUNNER'S WORLD* MAGAZINE

**Gabby McNary** who has tested positive for the HD gene, ran the Chicago Marathon (her first) to honor her mother who she lost to the disease five years ago. She also raised over \$4,000 for HDSA. Her inspiring story was featured in the October 14 edition of *Runner's World*.



Gabby McNary comforts her Mom.

## CHARITY NAVIGATOR AWARDS HDSA 4 STARS — ITS HIGHEST RATING — FOR THE FOURTH CONSECUTIVE YEAR

*"We are proud to announce Huntington's Disease Society of America has earned our fourth consecutive 4-star rating. This is our highest possible rating and indicates that your organization adheres to sector best practices and executes its mission in a financially efficient way. Attaining a 4-star rating verifies that Huntington's Disease Society of America exceeds industry standards and outperforms most charities in your area of work."*



*Only 20% of the charities we evaluate have received at least 4 consecutive 4-star evaluations, indicating that Huntington's Disease Society of America outperforms most other charities in America. This exceptional designation from Charity Navigator sets Huntington's Disease Society of America apart from its peers and demonstrates to the public its trustworthiness."*

**Michael Thatcher**, President & CEO, Charity Navigator

## HDSA LISTED IN TOP 10 VOLUNTEER OPPORTUNITIES IN NEW YORK CITY BY GREAT NONPROFITS

A woman whose mother was diagnosed with Huntington's disease forwarded the following comment to [greatnonprofits.org](http://greatnonprofits.org) about HDSA:



*"I am a daughter whose mother was diagnosed with HD, which I knew nothing about until I found this organization. It not only answered the billions of questions I had, but also provided me with emotional support from now friends. It gives me a sense of security knowing I am not the only person in the world going through this. This organization in a way saved my life. I was overwhelmed and ready to give up and they would NOT let that happen. For that I will always be truly thankful. This is an organization that helps people in every way possible. Thank you for all you have done and continue to do every day. I will always be a proud volunteer HDSA."*



# 2019 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 & volunteers.

Here are just a few!

Special thanks to our National Team Hope Sponsors

**Genentech**  
A Member of the Roche Group

**teva**

## PACIFIC REGION



**San Diego Team Hope Walk**  
San Diego Chapter  
\$115,000

**San Francisco Team Hope Walk**  
Pacific Region  
\$65,000

**Los Angeles Team Hope Walk**  
Los Angeles Chapter  
\$65,000

## SOUTH CENTRAL REGION

**Fairways for Hope**  
Rocky Mountain Chapter  
\$38,320

**Denver Team Hope Walk**  
Rocky Mountain Chapter  
\$34,700

**Anita Sabedra Team Hope Walk**  
South Central Region  
\$28,100



## UPPER MIDWEST REGION



**Twin Cities Team Hope Walk**  
Minnesota Chapter  
\$42,400

**South Dakota Team Hope Walk**  
South Dakota Chapter  
\$37,100

**Iowa Hoop-A-Thon Tour**  
Iowa Chapter  
\$27,000

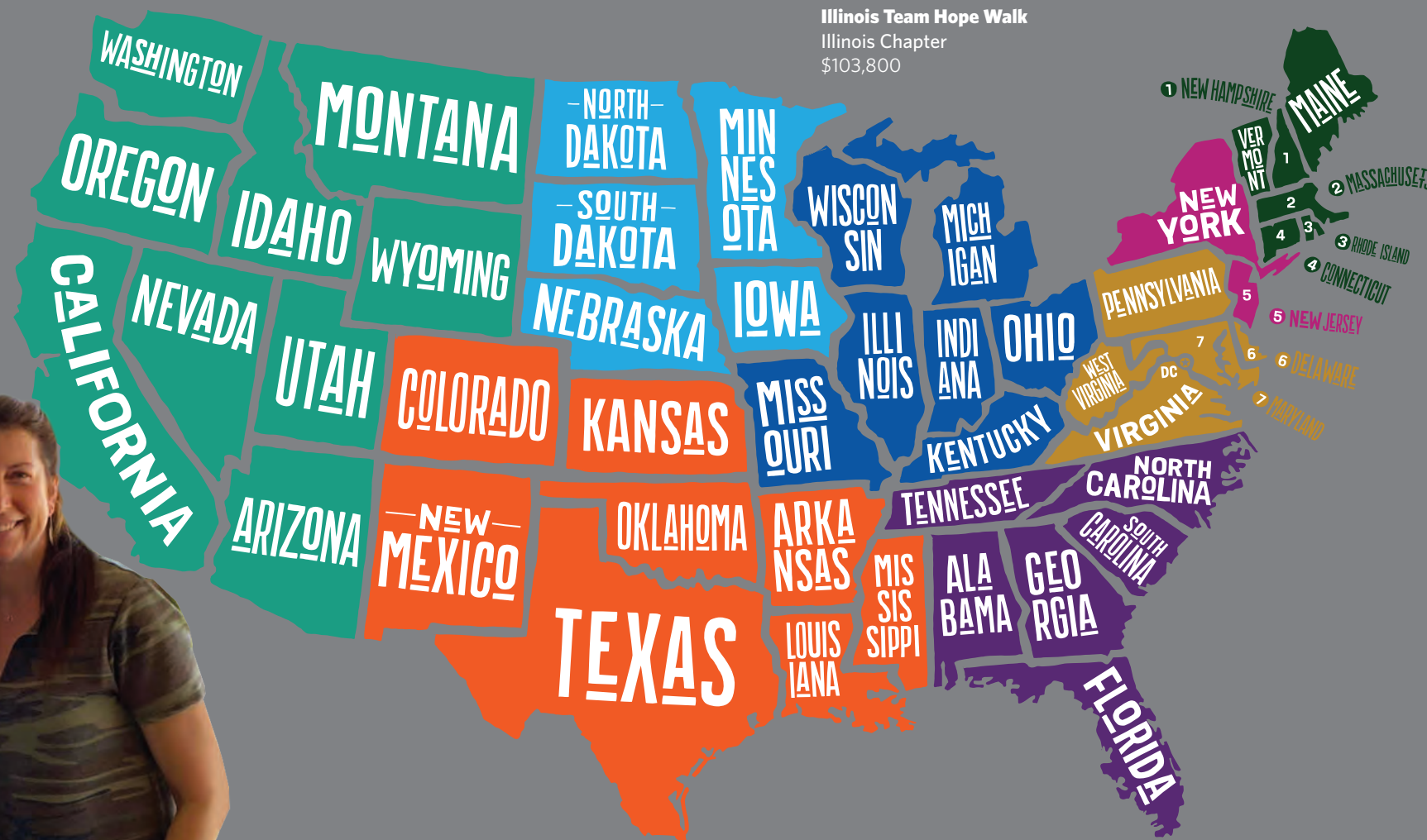
## GREAT LAKES REGION



**Sparkle Celebration of Hope**  
Northeast Ohio Chapter  
\$185,000

**Chicago Celebration of Hope**  
Great Lakes Region  
\$129,900

**Illinois Team Hope Walk**  
Illinois Chapter  
\$103,800



## NEW YORK / NEW JERSEY REGION

**New York City Team Hope Walk**  
Greater New York Chapter  
\$116,300

**Hudson Valley Team Hope Walk**  
New York/New Jersey Region  
\$83,800

**Celebration of Hope Dinner**  
Albany Chapter  
\$90,835



## MID-ATLANTIC REGION



**Team Hope Walk**  
Chesapeake Affiliate  
\$32,300

**Manassas Team Hope Walk**  
Mid-Atlantic Region  
\$30,797

**Philadelphia Team Hope Walk**  
Eastern Pennsylvania Chapter  
\$30,000

## SOUTHEAST REGION

**21<sup>st</sup> Annual Cure HD Golf Tournament**  
Tennessee Chapter  
\$124,129

**28<sup>th</sup> Annual Cure HD Triathlon/Duathlon/Aquabike 2019**  
South Florida Chapter  
\$64,275

**Atlanta Team Hope Walk**  
Georgia Chapter  
\$38,203

## NEW ENGLAND REGION



**New England Region Celebration of Hope Gala**  
New England Region  
\$62,500

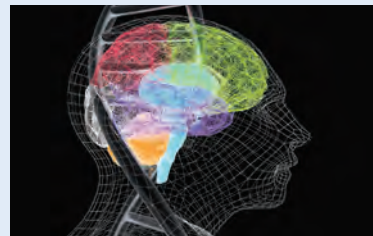
**Boston Team Hope Walk**  
Massachusetts Chapter  
\$52,650

**Tewksbury Team Hope Walk**  
Massachusetts Chapter  
\$48,000



# RESEARCH FUNDING PROGRAMS

## 2019 HUMAN BIOLOGY PROJECT FELLOWSHIPS



In October of 2019, HDSA awarded five grants under the Society's largest research initiative, the **HDSA Huntington's Disease Human Biology Project**. These grants, totaling \$575,000, represent HDSA's patient-centric research focus which brings basic and clinical researchers together to facilitate Huntington's disease science in the human condition. Applicants worldwide proposed projects addressing HD through small clinical studies or donated human samples. This year's winners hail from Scotland, Spain, and the United States.



**Vilija Lomeikaite, PhD candidate**  
*University of Glasgow*

Vilija will work on improving the existing methods to detect an increase in CAG repeats in certain cells of the body and brain during the course of HD.



**Danielle Larson, MD**  
*Northwestern University  
Feinberg School of Medicine*

Dr. Larson will study whether remote "telemedicine" visits with a neurologist could be just as helpful as in-person visits for an HD patient or family.



**Ricardo Mouro-Pinto, PhD**  
*Massachusetts General Hospital  
and Harvard Medical School*

Dr. Mouro-Pinto will focus on the biology of CAG repeat expansion in hopes of developing drugs to stop this process.



**Osama Al Dalahmah, MD**  
*Columbia University*

Dr. Al Dalahmah will examine how astrocytes, the brain's support cells, change over the course of HD to become harmful versus helpful.



**Saul Martinez-Horta, MsC,**  
*Sant Pau Hospital, Barcelona*

Saul will examine what kinds of changes are happening in the brain and blood when HD patients begin to have difficulty with planning and memory.

## Highlights from Previous HD Human Biology Project Fellowships

### Madeleine Sharp, MD

*2016 Human Biology Fellow,  
Postdoctoral Research Fellow, McGill University*

The overall goal of Madeleine's project was to uncover the mechanisms underlying common cognitive and behavioral symptoms of HD. She designed tasks to detect subtle changes in learning and memory, even in pre-symptomatic carriers of the HD gene. She exceeded her enrollment goals with a total of 79 HD patients, some of whom were recruited at HDSA's National Convention. This work is impactful from the perspective of early diagnostics as well as potential interventions. Certain cognitive tasks shown to create long-lasting improvements in memory and reward processing could potentially be powerful and safe approaches to treating early changes in thinking.



### Marina Papoutsis, PhD

*2017 Human Biology Fellow,  
Postdoctoral Researcher, University College London*

Marina is a skilled statistician whose project focused on the concept of "cognitive reserve," the idea that intelligence, education, or an intellectually stimulating lifestyle can be protective or delay cognitive problems for people with the HD gene. In 2019 she completed an analysis showing that HD patients with higher levels of education or a higher IQ had a slower rate of decline in mental abilities. This knowledge could be applied to design stimulating interventions, encourage young people in HD families to follow intellectual pursuits, or to stratify patients in clinical trials.



### Richard Hickman, MD

*2018 Human Biology Fellow,  
Neuropathology Fellow, Columbia University*

Richard's HDSA funding is allowing him to work closely with **Dr. Jean-Paul Vonsattel** to learn the art of HD brain banking, an invaluable skill that enables researchers to use donated human brain tissue. His HDSA fellowship also helped him to transition to an assistant faculty position at Columbia University. He is working with autophagy expert **Dr. Ai Yamamoto** to explore how the brain's waste disposal systems handle toxic huntingtin protein. Beyond potential discoveries that could help harness the power of the cell's clean-up crew to combat HD, the skills required to make use of precious brain donations from HD families are highly sought after.



## 2019 DONALD A. KING SUMMER RESEARCH FELLOWSHIPS

In April of 2019, four exceptional undergraduate students were awarded HDSA's **Donald A. King Summer Research Fellowships**. These awards are named in honor of Donald King, who served as HDSA Board Chairman from 1999 to 2003 and worked tirelessly to advocate for HD families until his death in 2004. In order to further meaningful discoveries about Huntington's disease and ensure that bright young scientists are steered towards the field, this program supports



**Zach Cook**  
*Brown University*

Zach spent the summer working with **Dr. Marc Tatar**, testing effectiveness of drugs in a fruit fly (*Drosophila*) model of Huntington's disease.



**Chloe LaRochelle**  
*University of Central Florida*

Chloe worked under the guidance of **Dr. Amber Southwell** on a project investigating aggression in HD mice.



**Alexandra Putka**  
*Duke University*

Alexandra worked in the laboratory of **Dr. Audrey Dickey** to elucidate how altered function of a protein called PPAR contributes to HD pathology.



**Colleen Strohlein**  
*University of Pittsburgh*

Colleen spent the summer working in the laboratory of **Dr. Robert Friedlander**, to investigate whether phosphorylation of huntingtin protein affects its localization to mitochondria.

## 2019 BERMAN-TOPPER FAMILY HD CAREER DEVELOPMENT FELLOWSHIPS

As part of HDSA's commitment to developing the next generation of passionate and innovative Huntington's disease scientists, the **Berman-Topper Family HD Career Development Fellowships** provide up to \$80,000 of funding per year for three years to young scientists and clinicians who desire to make HD part of their long-term career plan. These prestigious awards are made possible due to the generosity of the **Berman** and **Topper** families and **CHDI Foundation**. HDSA's Scientific Advisory Board reviewed applications from researchers from all around the world, and HDSA was able to award two scientists the 2019 Berman-Topper Fellowship — **Dr. Lauren Byrne** and **Dr. Nicholas Caron**.



*Dr. Nicholas Caron*

Dr. Byrne is working under the guidance of **Dr. Ed Wild** at University College London. Her project will better prepare the field for future disease prevention studies by researching how early in life we can detect changes in the neurofilament light (NfL) protein in persons with the HD mutation.

Dr. Caron is guided by **Dr. Michael Hayden** at the University of British Columbia. He will investigate novel ways to enhance the delivery of huntingtin lowering antisense oligonucleotides across the blood-brain barrier.



*Dr. Lauren Byrne and mentor Dr. Ed Wild at HDSA's Convention in Boston.*



RESEARCH



ADVOCACY



EDUCATION



YOUTH PROGRAMS



SUPPORT & SERVICES



DISABILITY PROGRAM



# HDSA 2019 MISSION REPORTS

# RESEARCH

BY GEORGE YOHLING, Ph.D.



## To Keep our HD Momentum Going We Must Have Even Greater Goals

In last year's *HDSA Research Report*, I stated, "I know that the HD families around the world will be ready to answer the call for brave research volunteers to get disease-modifying trials completed... quickly."

However, I could not have predicted just how quickly!

After years of waiting, in 2019 the HD community was rewarded with a spree of potential disease-modifying clinical trials. With such anticipation and demand, the **Natural History** and **GENERATION-HD1** studies from **Roche-Genentech**, the **Precision HD2** trial from **Wave Life Sciences**, and the **Signal** study from **Vaccinex** all completed US recruitment this year, at record speed.

While we await results from these studies, the HD research momentum continues. This year, **uniQure** began the first ever gene therapy trial for HD, and several other companies are moving towards this

goal. Recent success in gene therapy for spinal muscular atrophy provides a strong sense of optimism that this approach could alter the course of HD, too. **Novartis** also announced plans to launch a Phase 2 trial investigating an oral huntingtin-lowering drug.

A record number of HDSA Convention attendees in Boston, MA were treated to a presentation



Dr. Craig Mello

by **Dr. Craig Mello**, Nobel Laureate and discoverer of the science that has enabled huntingtin lowering trials to become a reality.

Dr. Mello and colleagues announced the formation of a new company that will try to treat HD. This is one of dozens now currently pursuing HD as a primary indication in their business plan.

While the light of hope now shines brighter for all of us, much work remains before HD becomes a thing of the past. That work requires the voices and the continuing participation of HD families. In 2019, HDSA continued to enable families to learn about and participate in HD research, through **HD Trialfinder**, our research blog and webinars, support of **HD Buzz**, the international **Coalition on Patient Engagement (HD-COPE)**, and more.

## FOR IMMEDIATE RELEASE

### UPDATE: Wave Life Sciences Shares Promising Clinical Trial Results

(Dec. 30, 2019) **Wave Life Sciences** has announced the top-line results of the **PRECISION-HD2** study. First and foremost, the drug was safe and well-tolerated in people with HD: there were no dangerous side effects. Furthermore, participants who received the drug had lower levels of toxic huntingtin protein at the end of the study. Because of these promising safety and huntingtin-lowering results, Wave will be adding a new group of participants to both **PRECISION** studies, who will receive a higher dose of the drug. The results of both trials are expected in the second half of 2020.

The inspiring scientific progress within the HD research community this year gives me confidence that 2020 will bring generations of HD families one step closer to relief.

**Thank you for all you do!**



**GEORGE YOHLING, Ph.D.** is HDSA's Chief Scientific Officer and Chief Mission Officer

# ADVOCACY

BY JENNIFER SIMPSON, LCSW

2019 saw positive growth and chance in our advocacy agenda! We were lucky to have **Catherine Finley** of **Thorn Run Partners** join us in the fight to pass the **HD Parity Act** as the leader of our Washington D.C.-based advocacy efforts. In May, **Representatives Kinzinger** (R-IL) and **Pascrell, Jr.** (D-NJ) introduced the HD Parity Act in the House alongside their partners **Senators Gillibrand** (D-NY)



Rep. Adam Kinzinger (R-IL)



Rep. Bill Pascrell, Jr. (D-NJ)



Sen. Kirsten Gillibrand (D-NY)



Sen. Bill Cassidy (R-LA)

and **Cassidy** (R-LA) in the Senate. The HD Parity Act (*HR 2770/S 1476*), is a bill that HDSA and advocates have been fighting to pass for a decade, and we are working hard as we can to see this bill cross the finish line this Congress. In July, more than 20 advocates from across the country joined HDSA's President and CEO **Louise Vetter** to advocate with members of the Senate Finance Committee, asking them to advance the HD Parity Act through committee. But we didn't stop there. Chapter and Affiliate members, Center of Excellence directors, Social Workers and allies continued to work throughout 2019, sending messages to Members of Congress, inviting other community members to join them in advocacy, as well as coordinating in-district meetings. Advocates in Ohio, Indiana and New Jersey met with Senators and Representatives right at home, engaging their Members of Congress, building relationships, and putting human faces to the advocacy being done behind the scenes in D.C. The impact of these meetings, contacts and relationships is incalculable, and invaluable.

HDSA was also asked to take part in a neurological conditions summit held at the Centers for Disease Control on the growing **National Neurological Conditions Surveillance System (NNCSS)**. The NNCSS was developed as part of the **21<sup>st</sup> Century**



**Cures Act of 2016** in an effort to better capture prevalence and incidence data on key neurological conditions on a national scale. Having accurate information on the incidence and prevalence of Huntington's disease would be invaluable in order to better direct clinical and support resources around the country. HDSA continues to advocate with the CDC to grow the NNCSS to include Huntington's disease, and better assess the impact of HD on U.S. families.



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

# EDUCATION

BY DEBRA LOVECKY, MS

2019 was an exceptional year for HDSA educational efforts. Thanks to a generous unrestricted educational grant from **Genentech**, HDSA was able to support 59 educational events that ranged from full day conferences to half-day meetings to support group guest speakers. This compares favorably with 2018 when HDSA supported 49 educational events. Our thanks to the creativity and budget savvy of our event organizers who used every one of our grant dollars wisely.



In addition to outstanding programming in the areas of care, advocacy and youth, several larger conferences received a clinical trial update from Genentech as well as information about advances in HD 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. Almost 2,700 HD family members and healthcare professionals attended these events with six multi-track state conventions attracting more than

100 family members to each. HDSA thanks Genentech for their generous unrestricted educational grant which made these events possible.

In the area of professional education, HDSA launched a new free three year continuing education course in partnership with the **American Occupational Therapy Association (AOTA)**. We anticipate that it will be as well received as the prior three year course which awarded more than 2,200 Continuing Education Units (CEUs) to community-based occupational therapy specialists.

In early 2020, HDSA will launch a new three year continuing education course with the **American Society of Genetic Counselors (NSGC)** that will provide the information community based genetic counselors will need to counsel and assist at-risk individuals contemplating HD genetic testing.

HDSA was invited to present two posters at the annual **Huntington Study Group** meeting in Sacramento CA. Each poster focused on HDSA's professional education efforts and partnerships with AOTA and **Medscape** (which awarded more than 5,000 CEUs to healthcare professional in 2018).

As always, HDSA is pleased to have featured so many of our HDSA Center of Excellence staff in these continuing education efforts.



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



# YOUTH PROGRAMS

BY JENNIFER SIMPSON, LCSW

2019 saw the expansion of HDSA's stable of youth support programs, rolling out our **Youth Social Worker Pilot Program** and the integration of these two social workers into the world of youth work. In 2019, the **HDSA National Youth Alliance (NYA)** held their four youth retreats around the country, returning to Pittsburgh and New Orleans and introducing Chicago and Sacramento as new sites. As we look to 2020, expect more new cities to be added to our rotating sites for **NYA Youth Retreats**. With our Youth Social Workers joining us in Chicago and Pittsburgh, young people can anticipate even more support in 2020 as we bring on two additional

youth social workers. HDSA and the NYA brought nearly 90 young people out to our youth retreats in 2019, providing them with information from experts at **HDSA Centers of Excellence**, support from social workers, and integrated improv and art therapy workshops.

The NYA also funded more than 60 young people to attend HDSA's largest ever **National Convention** in Boston through full and partial scholarships. The NYA also supported their **Regional Lead Program**, encouraging chapters and affiliates, as well as local social workers, support groups and youth social

workers, to utilize them for peer outreach and support. Regional Leads also took center stage during a **2019 advocacy trip to Washington D.C.**, using their stories to influence leaders to advance legislation important to the HD community. Here's to more incredible experiences, growth and support for young people impacted by HD in 2020!



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



# SUPPORT & SERVICES

BY ANNE LESERMAN, LCSW

**Ask a social worker!** Families and many professionals ask HDSA supported social workers questions about genetic testing, long-term care placement, locating resources in their community, accessing benefits and getting information and support about the disease. Families find it comforting to talk with someone who understands the complexities of HD.

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 47 states. Our social work professional training brought 68 social workers together prior to convention in

Boston. 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 for families and professionals and refers to the chapter and regional social workers who respond to thousands of requests. 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 **HDSA National Youth Alliance (NYA)** retreats.

Many families find support and a listening ear at HDSA in person support groups that are available in many states. Our on-line groups are open to those around the country. There are groups for caregivers, those at risk for HD, those early in the course of their illness, parents caring for children with HD and those in HD families that will not get HD. Groups help families understand and normalize the symptoms that can occur in HD persons. Caregivers and HD persons can all benefit. Individual counseling sessions are also offered through **American Well® (www.amwell.com)**, a telehealth program. Many continue to take advantage of free counseling sessions from mental health professionals in their state that are knowledgeable about Huntington's disease.



Check out the **HDSA website (www.HDSA.org)** and use the **Locate Resources** button to find services in your area. **Ask a social worker!**



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



# DISABILITY PROGRAMS

BY ALLISON BARTLETT, ESQ.

In 2019, HDSA unveiled its new **disability program** thanks to the addition of disability attorney, **Allison Bartlett, Esq.**, who specialized in the representation of clients with rare, chronic conditions, like Huntington's disease, to navigate them through the complex disability system. She works directly with families and social workers to provide advice, assistance, and resources for the Social Security disability process. We have assisted and provided educational resources to approximately 91 social worker

requests and 222 HD families via phone and email regarding the Social Security disability process and the appropriate next steps for the disability application in the areas including: when



to start the disability process, tips for submitting a disability application, health insurance, work credits and disability eligibility, and case specific disability questions.

HDSA launched the **Disability Chat Webinar Series** in September 2019 to cover a wide range of disability topics for families and social workers. Disability chat webinars are hosted every other month and provide an in-depth look at different aspects of the Social

Security disability process, including eligibility criteria, work credits, and the 5-step disability evaluation process. To date, Disability Chat has had 119 live views and 441 recorded views. HDSA has also expanded the **'Disability Benefits and HD'** section (under *Find Help, Healthcare & Future Planning*) on its website to include new disability resources. Several new resources were created for families and social workers this year to help with the Social Security disability application process,

including a *Disability Booklet, Wellness Journal, and Social Security Disability Application Tips.*

**If you have questions about Social Security disability or general disability topics, please contact Allison Bartlett, Esq. at 212-242-1968, ext. 218**



**ALLISON BARTLETT, ESQ** is HDSA's Manager of Disability Programs.



Please Join Us!



**35th ANNUAL  
HDSA  
CONVENTION**

**NEW ORLEANS**

**JUNE 4-6, 2020**

Save the Date!

Join us for the 35<sup>th</sup> Annual HDSA Convention  
in the Big Easy at the Sheraton New Orleans Hotel.

**JUNE 4-6, 2020, NEW ORLEANS, LA**

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



**MISSION**

To Improve the Lives  
of Everyone Affected by  
Huntington's Disease  
and Their Families.

**VISION**

A World Free of  
Huntington's Disease.

**BOARD OF TRUSTEES**

**E.J. Garner**  
Chair

**Victor Sung, M.D.**  
Chair-Elect

**Arik Johnson, Psy.D.**  
Past Chair

**Kamran Alam**  
Treasurer

**Jenne Coler-Dark**  
Secretary

**Dan Brennan**

**Stacy Coen**

**Wendy Erler**

**Donald Higgins, M.D.**

**Jay Hughes**

**Jonathan Klein, Esq.**

**Teresa Srajer**

**Leslie Thompson, Ph.D.**

**Daniel S. Vandivort**

**Vicki Wheelock, M.D.**

**STAFF LEADERSHIP**

**Louise Vetter**  
President and  
Chief Executive Officer

**Rosemary Coluccio**  
Chief Operating Officer

**Christopher Cosentino**  
Director of Marketing  
and Communications

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

**Jamison Skala**  
Director of Development

**George Yohrling, Ph.D.**  
Chief Scientific Officer and  
Chief Mission Officer





505 Eighth Avenue  
Suite 902  
New York, NY 10018

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

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



© 2020 Huntington's Disease Society of America  
All Rights Reserved.