

Huntington's Disease Society of America

# HDSA 2022 YEAR IN REVIEW

RESEARCH

EDUCATION

YOUTH PROGRAMS

ADVOCACY

DISABILITY PROGRAMS

SOCIAL SERVICES

# CONTENTS

President & CEO's Message.....	<b>1</b>
HDSA Centers of Excellence.....	<b>2</b>
37 <sup>th</sup> Annual HDSA Convention.....	<b>4</b>
2022 HDSA Highlights.....	<b>6</b>
2022 Freeze HD.....	<b>12</b>
2022 HDSA Regional Events Highlights.....	<b>14</b>
2022 HDSA Mission Reports.....	<b>16</b>
Advocacy.....	<b>18</b>
Education.....	<b>19</b>
Research.....	<b>20</b>
Social Services.....	<b>21</b>
Disability Programs.....	<b>22</b>
Youth Programs.....	<b>23</b>
38 <sup>th</sup> Annual HDSA Convention.....	<b>24</b>
HDSA Leadership.....	<b>IBC</b>
HDSA's Mission & Vision.....	<b>BC</b>
HDSA Contacts & Services.....	<b>BC</b>

# PRESIDENT & CEO'S MESSAGE

Dear Friends of HDSA,



2022 marked a return to togetherness for families affected by Huntington's disease. After several years of virtual and hybrid events, this year represented a return to in person events

and with it, a celebration of the strength of the HD community. HDSA and the HD community is resilient, and I cannot thank you enough for your continued support and commitment to fighting this devastating disease.

One of the most anticipated events was the **37<sup>th</sup> Annual HDSA Convention** where we welcomed more than 500 guests to the Marriott Marquis in Atlanta, Georgia. Being our first major in-person event in three years, we capped the number of attendees and made adjustments to our programming for folks to test the waters as we return to normalcy. We knew a number of community members were not ready to return in person just yet, so for the first time we offered a full live-stream of all the HDSA Convention sessions so folks could participate from the comfort of their homes around the world. **In 2023, we look forward to removing the attendance restrictions when we head to New Orleans on June 1<sup>st</sup>-3<sup>rd</sup>.**

Unfortunately, the excitement of rejoining friends and family was subdued this year by multiple clinical trials for potential HD therapeutics facing

delays and setbacks. We know that drug discovery is difficult and cumulative, so our challenge is to ensure that the community is able to learn from each setback and that we maintain our momentum in supporting new research as it moves forward.

**Right now, there are more biopharmaceutical companies working on HD than ever before, collecting vital data that is shaping a healthier future. This is all possible because of the brave HD family members who participate in clinical research.** They are the key to the development of new treatments for HD and we are so grateful.

Early in 2022, we were proud to announce that the **HDSA Centers of Excellence network grew to 55 comprehensive care clinics** across the country with 10 partner locations. Our investment of nearly \$2 million means that HD families have more access to expert HD care than ever before. Additionally, to continue supporting HD research efforts, **HDSA contributed more than \$3 million towards HD research programs in 2022.** We continued to fund our Berman-Topper Family HD Career Development Fellowship, HD Human Biology Projects and Donald A. King Summer Research Fellowships to ensure more scientists are working on HD in the lab.

**In October, the 8<sup>th</sup> Annual Freeze HD returned to an in-person event and raised more than \$200,000!** This amazing night honored actor **Jason Ritter** and the entire **Ritter Family** for their extraordinary commitment to the HD community. Hosted by

**Dustin Brayley** from the Trans-Siberian Orchestra and Broadway Star **Meredith Patterson**, the event welcomed several well-known celebrities and featured amazing performances and an online auction to support the HDSA mission.

Every HDSA mission program and service was able to grow and support more families in 2022 in large part to the amount of local awareness that was generated throughout the year. HDSA recorded more than **six billion** (yes — “billion” with a “b”!) media impressions — the most ever for our organization. Clearly more people are talking about HD and taking advantage of HDSA's world class resources from coast to coast.

Thank you for making all of HDSA's vital programs and services possible. We welcome 2023 with renewed energy to implement our strategic plans to do more to improve the lives of everyone affected by Huntington's disease. We are driven every day by our goal to provide help and hope to HD families everywhere.

**At HDSA, Family is Everything. Thank you for your continued support.**

Sincerely,

**Louise Vetter**  
HDSA President and CEO



# HDSA CENTERS OF EXCELLENCE

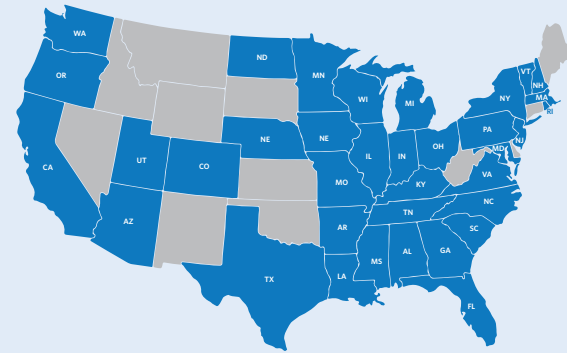
## HDSA Awards Nearly \$1.9 million to Network of Fifty-Five HDSA Centers of Excellence

Early in 2022, the Huntington's Disease Society of America announced that fifty-five outstanding Huntington's disease care facilities are being awarded the designation of **HDSA Centers of Excellence** for 2022. In addition to the 55 grant funded clinics, ten regional partner sites were also named ensuring expert HD care at 65 distinct medical facilities in 35 states across the nation. **This year, \$1,896,333 has been awarded to the HDSA Centers of Excellence program.**

The HDSA Centers of Excellence are multi-disciplinary care teams with expertise in Huntington's disease that share an exemplary commitment to providing comprehensive care for this complex, hereditary, neurodegenerative disease. **The expansion from 54 sites in 2021 to 55 sites in 2022 comes from the addition of Oregon Health & Science University as the newest HDSA awarded clinic.** Launched in 1998, the HDSA Center of Excellence network has grown from 20 sites as recently as 2015.

**In addition, the HDSA Center of Excellence network expanded from eight partner sites in 2021 to 10 in 2022.** The designated ten Partner Sites are: University of South Alabama, Kaiser Permanente (CA), St. Luke's University Health Network (Bethlehem, PA), Central Florida Center for Huntington's Disease (Winter Park and Orlando, FL), Covenant Medical Group Neurology (Lubbock, TX), Texas Movement Disorders Specialist PLLC, University of Texas Health San Antonio, Selkirk Neurology, (Spokane, WA), Cole Neuroscience Center (University of Tennessee Medical Center) and University of Tennessee (Erlanger Medical Center).

"The Huntington's Disease Society of America is committed to supporting the best possible care for families affected by Huntington's disease," said **Dr. Victor Sung**, Chair of HDSA's National Board of Trustees and Director of the HDSA Center of Excellence at The University of Alabama, Birmingham. "Continuing to expand the reach of the HDSA Centers



of Excellence network allows more families across the country to have access to these world-class clinics."

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 to all clinics in the United States who share HDSA's commitment to high-quality, comprehensive care and access to clinical research.

**Louise Vetter**, President & CEO of HDSA added, "We are thankful for the incredible work that the clinics provide HD families. It is because of the generosity of the HD community and our partners that we are able to continue to expand and support the very best in HD care."

## The 2022 HDSA Centers of Excellence Network

Albany Medical College (NY)  
 Barrow Neurological Institute (AZ)  
 Beth Israel Deaconess Medical Center (MA)  
 Cleveland Clinic (OH)  
 Columbia Health Sciences/NYS Psychiatric Institute (NY)  
 Duke University (NC)  
 Emory University (GA)  
 MedStar Georgetown University Hospital (DC)  
 Hennepin Health Care (MN)  
 Henry Ford Hospital (MI)  
 Indiana University  
 Johns Hopkins University (MD)  
 Massachusetts General Hospital  
 Medical University of South Carolina  
 Northwestern University (IL)  
 Ochsner Health System (LA)  
 Ohio State University  
 Oregon Health & Science University\*  
 Rocky Mountain Movement Disorders Clinic (CO)

Rowan University School of Medicine & Rutgers University RWJ Medical School (NJ)  
 Rush University Medical Center (IL)  
 Sanford Health (ND)  
 Stanford University (CA)  
 Stony Brook University Hospital (NY)  
 University of Alabama, Birmingham  
 • *Partner Site: University of South Alabama*  
 University of Arkansas  
 University at Buffalo (NY)  
 University of California, Davis Medical Center  
 • *Partner Site: Kaiser Permanente (CA)*  
 University of California, Irvine  
 University of California, Los Angeles  
 University of California, San Diego  
 University of California, San Francisco  
 University of Cincinnati (OH)

University of Colorado  
 University of Florida  
 University of Iowa  
 University of Kansas Medical Center  
 University of Louisville (KY)  
 University of Miami (FL)  
 University of Mississippi Medical Center  
 University of Nebraska Medical Center  
 University of Pennsylvania  
 • *Partner Site: St. Luke's University Health Network, Bethlehem, PA\**  
 University of Pittsburgh Medical Center (PA)  
 University of Rochester (NY)  
 University of South Carolina School of Medicine  
 University of South Florida  
 • *Partner Site: Central Florida Center for Huntington's Disease, Winter Park and Orlando, FL\**

\* Blue text indicates newly designated HDSA Center of Excellence or Partner Sites for 2022.

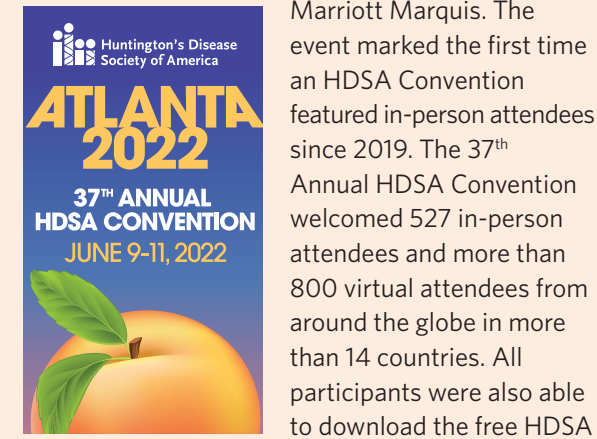
University of Texas Health Science Center at Houston, McGovern Medical School  
 • *Partner Site: Covenant Medical Group Neurology, Lubbock, TX*  
 • *Partner Site: Texas Movement Disorders Specialist, PLLC*  
 • *Partner Site: University of Texas Health San Antonio*  
 University of Utah  
 University of Vermont, Frederick Binter Center for Parkinson's Disease and Movement Disorders  
 University of Virginia  
 University of Washington (WA)  
 • *Partner Site: Selkirk Neurology, Spokane, WA\**  
 University of Wisconsin  
 Vanderbilt University Medical Center (TN)  
 • *Partner Site: Cole Neuroscience Center, University of Tennessee Medical Center*  
 • *Partner Site: University of Tennessee, Erlanger Medical Center*  
 Virginia Commonwealth University  
 Washington University School of Medicine (MO)





# 37<sup>TH</sup> ANNUAL HDSA CONVENTION

On June 9th-11th, the Huntington's Disease Society of America hosted the **37<sup>th</sup> Annual HDSA Convention** in Atlanta, Georgia at the Atlanta



Marriott Marquis. The event marked the first time an HDSA Convention featured in-person attendees since 2019. The 37<sup>th</sup> Annual HDSA Convention welcomed 527 in-person attendees and more than 800 virtual attendees from around the globe in more than 14 countries. All participants were also able to download the free HDSA

Convention app which allowed them to connect with other attendees, ask questions during sessions, get updates and much more.

"It was amazing to bring the HD community together again," said **Louise Vetter**, HDSA's President & CEO. "Despite limiting the number of in-person attendees, the magic and one-of-a-kind energy of the HDSA Convention was certainly present. Living with a rare disease can be isolating, so the togetherness of Convention is a powerful weapon in the fight to improve the lives of everyone affected by Huntington's disease."

On day one of the HDSA Convention, in-person attendees enjoyed the annual **Team Hope Walk** around the streets of Atlanta followed by a **Welcome Reception** with great food and music.

The second day began with a comprehensive and very entertaining research update during the **Opening Ceremony** from **Drs. Jeff Carroll and Ed Wild** from **HDBuzz.net**. Educational sessions were conducted throughout the day led by HD experts.

## Volunteer Awards Luncheon

The following were recognized for their outstanding service at the **Volunteer Awards Luncheon**:

- **Social Media Award**  
HDSA Los Angeles Chapter
- **Outstanding Achievement in Advocacy Award**  
HDSA Washington State Chapter
- **Outstanding Achievement in Board Development**  
HDSA Massachusetts & Rhode Island Chapter
- **Outstanding Achievement in Education or Family Services**  
HDSA Kentucky Chapter
- **Outstanding Achievement in Fundraising**  
HDSA Central Ohio Chapter
- **Affiliate of the Year Award**  
HDSA Omaha Affiliate
- **Chapter of the Year Award**  
HDSA Northeast Ohio Chapter

Day two was capped off with the annual **HDSA National Youth Alliance (NYA) Talent Show**. The HDSA NYA Talent Show raised more than \$21,000 to support youth scholarships to attend next year's HDSA Convention in New Orleans.



On the third and final day of the HDSA Convention began with the **Research Forum** and an amazing keynote from **Dr. Sarah Tabrizi** of University College London (UCL). After the final sessions, all those in attendance (both in-person and virtual) took part in the **HDSA Convention Awards Dinner & Gala** which included the emotional **Candle Lighting** ceremony to honor the HD community.

During the Awards Dinner, the **HDSA Center of Excellence at Emory University** was recognized for its 25<sup>th</sup> anniversary of providing multidisciplinary HD care.



## HDSA National Awards

-  **Excellence in Care**  
Jessica Marsolek (Minnesota)
-  **Youth Award**  
Ashley Pesi (Pennsylvania)
-  **Research Award**  
Dr. Sarah Tabrizi (University College London)
-  **Marjorie Guthrie Award**  
Heather Thurgood Wilmoth (Mississippi)
-  **Woody Guthrie Award**  
Kinser Cancelmo (Massachusetts)
-  **Person of the Year**  
Jesse Lis (Ohio)



Prior to Atlanta, the last in-person HDSA Convention was held in Boston, MA with more than 1,500 attendees. **HDSA plans to remove attendance restrictions** and bring back popular HDSA Convention activities to the **38<sup>th</sup> Annual HDSA Convention in New Orleans, LA on June 1-3, 2023.**



*Thank You!*

The Huntington's Disease Society of America would like to thank the following sponsors for making the 37<sup>th</sup> Annual HDSA Convention a success:

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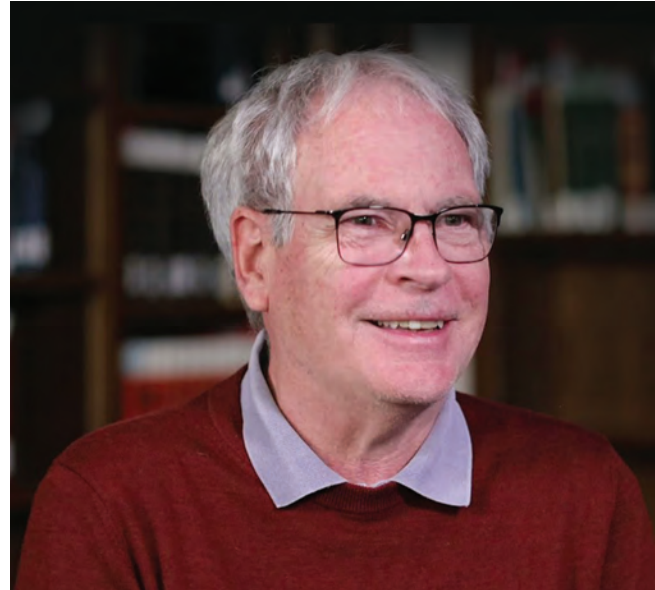
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- Spark Therapeutics




# 2022 HDSA HIGHLIGHTS



## Dr. Harry Orr Wins 2022 Kavli Prize in Neuroscience

**Dr. Harry Orr** is an American geneticist specializing in neurodegenerative diseases and is a member of **HDSA's Scientific Advisory Board. The Kavli Prize in Neuroscience** is awarded for outstanding achievement in advancing our knowledge and understanding of the brain and nervous system, including molecular neuroscience, cellular neuroscience, systems neuroscience, neurogenetics, developmental neuroscience, cognitive neuroscience, computational neuroscience, and related facets of the brain and nervous system. **Congratulations Dr. Orr!**




## Research Webinars

Throughout the year, **HDSA's Mission Team** kept the global HD community up-to-date on HD science news in **HDSA's Research Webinars** that can be found on HDSA's YouTube channel.

## HDSA Disability Chat Webinars and Disability Tips Blog

HDSA's **Allison Bartlett, Esq.** provided valuable disability resources and tips throughout the year on multiple platforms. **HDSA's Disability Chat Webinars, HDSA's Disability Tips Blog** and other disability resources can be found at [HDSA.org/disability](https://www.hdsa.org/disability).



## Board of Trustees Update

After serving his three-year term as Chair, **Dr. Victor Sung** has rotated into the Past Chair role and **Teresa Srajer** has been appointed Chair of HDSA's National Board of Trustees. **Jenne Coler-Dark**, who held the position of Secretary, has been named Chair Elect. To fill the Secretary vacancy, the Nominations and Governance Committee elected **Jay Hughes** as Secretary for a one-year term concluding at the 2023 Annual Meeting of the Board of Trustees.



*Teresa Srajer*

The HDSA National Board of Trustees have elected **Dr. Jeffrey Brown** to join the HDSA Board of Trustees for a three-year term.

**Dan Brennan, Stacy Coen** and **E.J. Garner** have also served their terms on HDSA's Board of Trustees and the Society thanks them for their extraordinary dedication to the HD community.

To learn more about HDSA's National Board of Trustees, please visit [HDSA.org/trustees](https://www.hdsa.org/trustees).

## Charity Navigator Four-Star Rating

In November, HDSA announced that its strong financial health and ongoing accountability and transparency has earned the coveted **Four-Star Rating** from **Charity Navigator**. This rating designates HDSA as an official **"Give with Confidence"** charity, indicating that our organization is using its donations effectively based on Charity Navigator's criteria. "We are delighted to provide the Huntington's Disease Society of America with third-party accreditation that validates their operational

## #MyCauseMyCleats 2022

With his family having been impacted by Huntington's disease, the NFL's Indianapolis Colts linebacker **Forrest Rhyne** raised HD awareness and support of HDSA when he wore customized HDSA cleats in his second NFL game on December 4<sup>th</sup> against the Dallas Cowboys. Forrest is the third NFL player to



*Forrest Rhyne from the Indianapolis Colts wore HDSA cleats as part of the NFL's #MyCauseMyCleats Campaign.*

excellence," said **Michael Thatcher**, President and CEO of Charity Navigator. "The Four-Star Rating is the highest possible rating an organization can achieve. We are eager to see the good work that the Huntington's Disease Society of America is able to accomplish in the years ahead."





## May: HD Awareness Month



### 31 Days, 31 Stories

In May HDSA once again shared powerful HD stories each day on social media throughout HD Awareness Month. HDSA's **31 Days, 31 Stories** campaign features different members of the HD community providing their perspective on HD and can be seen on HDSA's YouTube channel.



## What Huntington's Tells Us About Living Storytelling Event

On May 11th, HDSA partnered with **Stellar Storytelling** to host **"What Huntington's Tells Us About Living"** at the Regent Theatre in Arlington, MA. This moving event was sponsored by **uniQure** and featured six powerful stories from members of the HD community. The stories can be watched on HDSA's YouTube channel.



Speakers who shared their HD stories included (from left to right): Dr. Stephanie Bissonnette, Kinser Cancelmo, MaryAnn Emerick, Dr. Melvin Evers, Charles King, and Peggy McDonald.

## HEROCLIX FOR HUNTINGTON'S

ON MAY 5<sup>TH</sup>-8<sup>TH</sup>,  
SCOTT PORTER HOSTED  
THE SECOND ANNUAL "HEROCLIX  
FOR HUNTINGTON'S" EVENT AND  
RAISED MORE THAN \$26,000  
TO SUPPORT THE FIGHT  
AGAINST HD!



## HD Hockey Classic

On May 14<sup>th</sup>, HDSA faced-off against the **Huntington Society of Canada** at the inaugural **HD Hockey Classic**. The game featured several former professional and collegiate players including Stanley Cup Champions **Rob Scuderi**, **Colin White**, and **Jake Dowell**. The game was held at the Barnabas Health Hockey House in Newark, New Jersey — home of the New Jersey Devils.



Players included former NHL stars (l-r) Rob Scuderi, Colin White, and Jake Dowell, the 2013-14 recipient of the NHL's Fred T. Hunt Memorial Award for his outstanding work to raise HD awareness.

Above: Team HDSA in white, and Team Huntington Society of Canada in blue.

Below: A pre-game wager ends in good natured fun. As HDSA was the winning team, HDSA's CEO, Louise Vetter served Huntington Society of Canada's CEO Shelly Redman some humble pie.



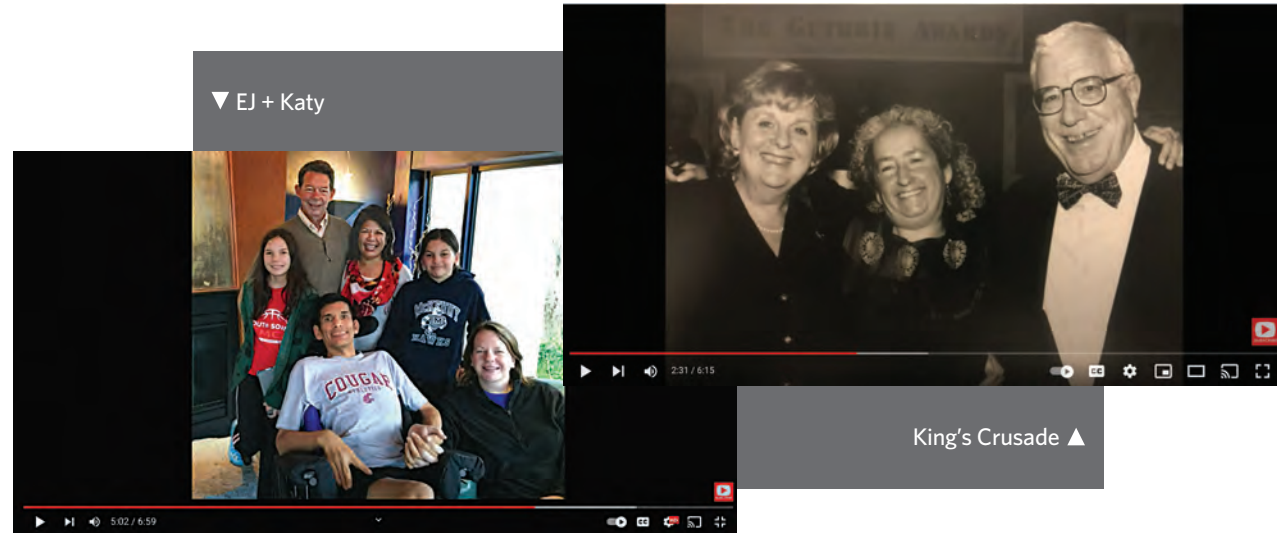


## HDSA Films

This year, HDSA produced short films featuring members of the HD community.

**EJ + Katy** shares the brave story of one family impacted by HD. **King's Crusade** is a two-part story that pays tribute to former HDSA Chairman **Donald A. King** and the family's shocking diagnosis.

Both can be viewed on HDSA's YouTube channel.



## #HDTV

Due to HDSA's record-breaking awareness campaigns, we are seeing more Huntington's disease storylines on TV shows than ever before. HDSA created the **#HDTV** initiative that shows HD mentions on your favorite shows and can be seen on HDSA's YouTube channel.

## HDSA Quick Question

In 2022, HDSA staff members answered common Huntington's disease questions during **HDSA's Quick Question series**. HDSA's Quick Question videos can be viewed on HDSA's YouTube channel.



10

## HDSA Corporate Partnership Program

**HDSA's Corporate Partner Program** invites current and new corporate partners to develop collaborative opportunities to support HD families' access to services and resources needed to navigate their Huntington's Disease journeys. Given HDSA's history of impact, family, and integrity, we seek to collaborate with partners who align with these values and advance our mission goals of care, cure, and community. Learn more, visit us at [HDSA.org/partnerships](https://HDSA.org/partnerships).



*Broda, which manufactures premium wheelchairs, seating products, and accessories for long-term care, is a proud participant in HDSA's Corporate Partnership Program.*

## TCS NEW YORK CITY MARATHON HDSA NYC Marathon Team

Twenty-three runners from across the United States and Canada participated in the **TCS New York City Marathon** on Sunday, November 6, 2022 to support the Huntington's Disease Society of America. By race day, the team had raised \$93,760. **Donations continued after the event and a total of \$107,000 was received!**



"We can't thank our runners enough for their commitment to fighting Huntington's disease," said **Louise Vetter**, President and CEO of HDSA. "The funds raised will go towards supporting HDSA's mission to improve the lives of everyone with HD and their families."



11



**Sean Riddle** recorded the team's fastest finish completing the 26.2-mile marathon in an impressive 4 hours and 4 minutes. Thank you **EisnerAmper LLP** for serving as this year's team jersey sponsor.

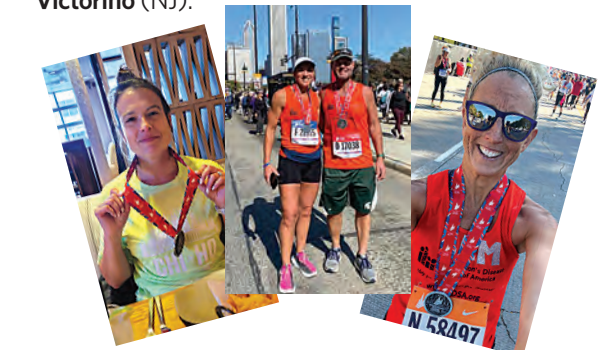
**Thank you Team HDSA:** Emalee Blumhagen (NY), Amy Bond (CA), Craig Bond (CA), Teresa Brooks (IA), Jordan Brown (TN), Craig Calo (NY), Kerry Cavanagh (MA), Samantha Cox (IL), Andrea Doepker (OR), Haley Falkenberry (NY), Lauren Hinkley (Washington, DC), Marie Elena Howe (PA), Hannah Joeckel (TX), Brett Kincade (TX), Todd Marentette (Wheatley, Ontario), Jessica Marsolek (MN), Arturo Pardavila III (NJ), Jeff Pucciarelli (FL), Sean Riddle (CT), Jon Rink (MI), Bianca Schwarz (UT), Jaylen Sheldon (LA) and Susan Wooten (IL).

## CHICAGO MARATHON Team Run for HD

This year, more than **\$106,000** was raised by **Team Run For HD at the Chicago Marathon** which is nearly \$25,000 more than we've ever made from our Chicago Marathon Team. We had 32 runners on the team this year and **Madeline Higdon** was the team's highest fundraiser who raised more than \$10,000!



**Thank you Team Run for HD:** Chelsea Beaulne (IL), Abigail Blixt (PA), Madison Brandt (MI), Kara Burley (NJ), Brianna Consigli (MA), Samantha Cox (IL), Jack Cribb (MI), Spencer Diehl (TN), Randy Hahn (WI), Heidi Heeke (IN), Madeline Higdon (IL), Lisa Hubbard (IA), Adrienne Lindsay (FL), Tom Malone (MA), Jessica Marsolek (MN), Erin Mason (MI), Joseph McGrath (IL), Samantha Miller (AZ), Peter Martinek-Jenne (NC), Jane O'Mahoney (ME), Bryce Ondell (IN), Brandon Patty (LA), JenLynn Parker (IL), Laura Pichotta (VT), Amanda Puckett (TN), Gail Shurlow (MI), Kevin Shurlow (NC), Bridget Slate (TX), Sarah Smith (CA), Hannah Sontz (NY), Sean Toler (IL) and Kristen Victorino (NJ).







After two years of virtual programs, the popular **Freeze HD** event to support the **Huntington's Disease Society of America** returned in person on Saturday, October 22, 2022 at the Avalon in Hollywood and **raised more than \$208,000!** The event honored **Jason Ritter** and the **Ritter Family** for their incredible support in the fight against Huntington's disease. **Jason, Nancy Morgan Ritter, Tyler Ritter** and **Leia Parma** were on stage to accept the honor. **Marianna Palka** and **Lucy Walker** introduced the honorees after showing the trailer of the 2014 HBO Films documentary, **The Lion's Mouth Opens**. The powerful short film, directed by Walker, followed

Marianna's HD testing journey and featured **Jason** and **Bryce Dallas Howard**.

The Eighth Annual Freeze HD was hosted by Broadway star **Meredith Patterson** (*42<sup>nd</sup> Street*) and **Dustin Brayley** (Trans-Siberian Orchestra) who performed several acts with their sons, **Billy** and **Maxwell**. Actor **Scott Porter** also performed a couple songs featuring two-time Grammy nominee **Matt Beckley**.

"Freeze HD is much more than a charity event for families affected by Huntington's disease. It is a call to action to stop this devastating brain disease in its

**Huntington's Disease Society of America**

EIGHTH ANNUAL

**FREEZE HD**



tracks with more awareness, care and science," said **Louise Vetter**, HDSA's President & CEO. "Since its visionary launch nine years ago by the Ritter family and Marianna Palka, this annual event has raised more than \$1.7 million to support HDSA's programs of help and hope. We are grateful to our host committee, sponsors and the Los Angeles community who join us in celebrating the strength of HD families while we fight for a healthier tomorrow."

The much-anticipated red carpet event featured an incredible auction, live entertainment, celebrity meet

and greet, surprise guests, and an exclusive VIP Afterparty.

**The Eighth Annual Freeze HD Host Committee** included: **Layla Alizada, Dustin Brayley, Angelique Cabral, India De Beaufort, Noel Fisher, Todd Grinnell, Humphrey Ker, Briana Lane, Melanie Lynskey, Kate Miner, Marianna Palka, Angel Parker, Meredith Patterson, Scott Porter, Jason Ritter, Kelly Thiebaud and Lucy Walker** as well as **Jessica Cain, Kipenzi Chidinma, Blake & Jenne Coler-Dark, David Cooper, Christopher & Lisa Davis, Jessica Etting,**

**Matt & Courtney Hamilton, Gentile Koosed, Justin Miner, Leia Parma, Kelsey Porter, Carly Ritter, Tyler Ritter** and **Nancy Morgan Ritter**.

Other special appearances by: **Ali Ahn, Wilson Bethel, Rachel Bilson, EJ Bonilla, Jason Canela, Debbie Gibson, Eric Edelstein, Debra Fisher, Zach Gilford, Seth Green, Jeremy Konner, Simon Helberg, Bryce Dallas Howard, Emma Hunton, Tricia LaFache, Sean Maguire, Chris Marquette, Tanya Memme, Dash Mihok, Nora-Jane Noone, Patton Oswalt, Judge Reinhold, Homer Simpson, Amy Yasbeck** and many more!



THE EIGHTH ANNUAL **FREEZE HD**

WAS SPONSORED BY:

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Jessica Cain  
Blake & Jenne Coler-Dark  
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Hamilton Land Development, Inc.  
Candace Jackson  
Tamar & Phil Koosed  
Carly Ritter  
Shawn Smith  
Doug Zatar



# 2022 HDSA REGIONAL EVENTS HIGHLIGHTS

## HDSA PACIFIC WEST REGION

- **Fairways for Hope**  
Rocky Mountain Chapter: \$65,982
- **Team Hope Walk**  
San Diego Chapter: \$46,946
- **Team Hope Walk San Francisco**  
Pacific West Region: 41,738
- **Team Hope Walk**  
Los Angeles Chapter: 36,947
- **Seattle Team Hope Walk**  
Washington Chapter: \$33,333

## HDSA MIDWEST REGION

- **Celebration of Hope**  
Northeast Ohio Chapter: \$223,000
- **Re-Prom Celebration of Hope**  
Wisconsin Chapter: \$158,000
- **Chicago Celebration of Hope**  
Upper Great Lakes Region: \$117,000
- **Loda Team Hope Walk**  
Upper Great Lakes Region: \$57,975
- **Liberty Team Hope Walk**  
Upper Great Lakes Region: \$55,168

## HDSA NORTHEAST REGION

- **New York City Team Hope Walk**  
Greater New York Chapter: \$158,667
- **Boston Team Hope Walk**  
MA/RI Chapter: \$119,250
- **New England Celebration of Hope**  
Northeast Region: \$60,916
- **Fishy Frolic 5K & Team Hope Walk**  
Albany Chapter: \$45,811
- **Jersey Shore 5K & Team Hope Walk**  
New Jersey Chapter: \$43,634

## HDSA SOUTH REGION

- **30<sup>th</sup> Annual HD Triathlon**  
South Florida Chapter: \$73,415
- **Hope for Huntington's Nashville Golf Tournament**  
Tennessee Chapter: \$28,845
- **Georgia Team Hope Walk**  
Georgia Chapter: \$26,603
- **GNTX Team Hope Walk**  
Greater North Texas Affiliate: \$25,298

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. The above are just a few!

Special thanks to our National Team Hope Sponsors

**Genentech**  
A Member of the Roche Group

**teva**

## HDSA PACIFIC WEST REGION

Alaska, Arizona, California, Colorado, Idaho, Montana, Nevada, New Mexico, Oregon, Utah, Washington, Wyoming



Fairways for Hope  
HDSA Rocky Mountain Chapter



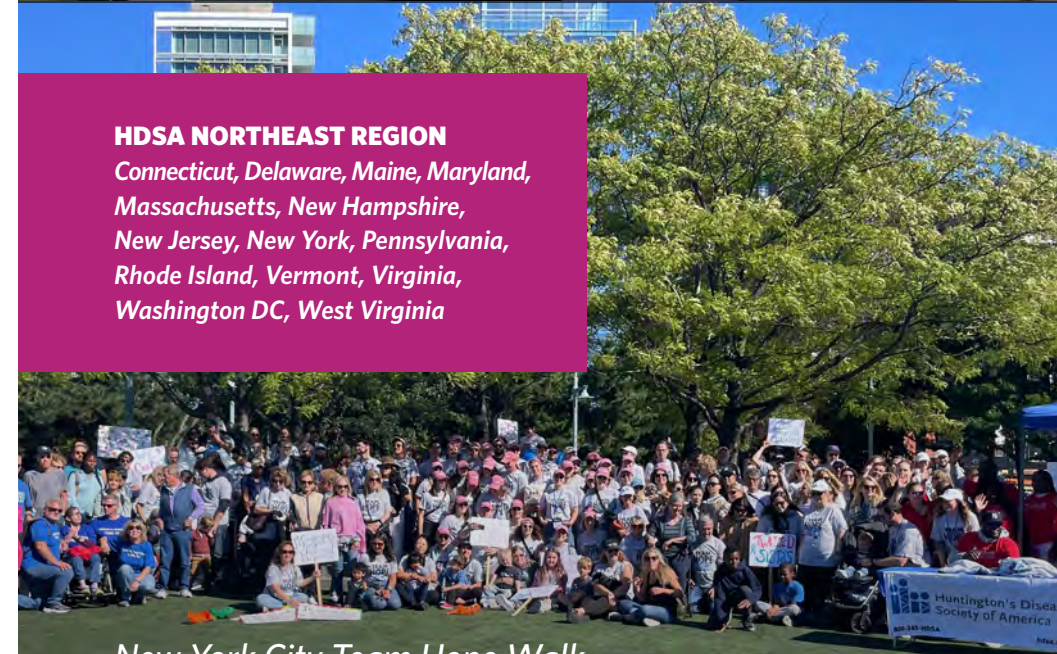
## HDSA MIDWEST REGION

Illinois, Indiana, Iowa, Kentucky, Michigan, Minnesota, Missouri, Nebraska, North Dakota, Ohio, South Dakota, Wisconsin

Celebration of Hope  
HDSA Northeast Ohio Chapter

## HDSA NORTHEAST REGION

Connecticut, Delaware, Maine, Maryland, Massachusetts, New Hampshire, New Jersey, New York, Pennsylvania, Rhode Island, Vermont, Virginia, Washington DC, West Virginia



New York City Team Hope Walk  
HDSA Greater New York Chapter



## HDSA SOUTH REGION

Alabama, Arkansas, Florida, Georgia, Kansas, Louisiana, Mississippi, North Carolina, Oklahoma, South Carolina, Tennessee, Texas

30<sup>th</sup> Annual HD Triathlon  
HDSA South Florida Chapter





# HDSA 2022 MISSION REPORTS



## Advocacy

by Arik Johnson, PsyD

The focus of HDSA Advocacy efforts in 2022 was two pieces of legislation, **HR 2050/S 868**, better known collectively as the **HD Parity Act**. Unfortunately, the HD Parity Act did not pass, nor was it included in the end of year Omnibus Appropriations bill in Congress. This news was disappointing, because the purpose of this legislation would have made it easier for people living with HD to qualify for Social Security Disability Insurance and would have removed the two year waiting period for



Medicare benefits. Feelings of frustration and being let down are understandable, but it is important to highlight the work done by the HDSA Advocacy Caucus and the entire HD community in the months leading up to this outcome.

The **HDSA Advocacy Caucus** is a dedicated group of volunteers who spearhead the grassroots advocacy efforts in raising Congressional awareness of the HD Parity Act. This group met monthly to discuss advocacy strategies and worked with HDSA staff on targeted campaigns. They fiercely championed the Act and used their voices to garner support for the legislation. Because of this group, the HD Parity Act had bipartisan support in both houses of Congress, with almost 200 co-sponsors in the House and 20 co-sponsors in the Senate. Our legislative consultant team in Washington DC, Thorn Run Partners, supported the HDSA Advocacy Caucus in this work by educating us on the processes of government and connecting the many moving pieces together.

This coordinated effort was amplified by the HD community voices who joined in a massive email campaign during the first two weeks of December 2022. Starting with messaging to six specific states, the people in CA, IL, LA, MA, NJ, and NY generated

over 750 messages sent to Congress. This was followed by a nationwide push leading to over 2,500 messages sent in five days. Again, despite the outcome with the HD Parity Act, we saw the HD community rally and are motivated by everyone who participated in this effort as we plan our advocacy strategy for 2023.

In addition to the HD Parity Act, HDSA continues to advocate for people living with HD in other ways. On a national level we work with HD consortiums and regulatory groups like the FDA, ensuring they understand the people impacted by the disease and not just the disease itself. Across the country HDSA volunteers and staff impact change, by providing education and resources to law enforcement, long term care facilities, and to local governments. This work is ongoing and needs are still being identified, but the power of this dedicated community drives us to continue to do more.



**Arik Johnson, PsyD**  
HDSA Chief Mission Officer  
[ajohnson@HDSA.org](mailto:ajohnson@HDSA.org)

## Education

by Debra Lovecky, MS

We can look back on 2022 and the continuing challenges posed by an ever evolving national health picture as a testament to the dedication and commitment of the HD community and our HDSA volunteers. Though circumstance may have dictated a quick pivot from a planned in-person educational event to a hybrid or fully remote gathering, our event organizers remained determined to host educational sessions for HD families throughout the year.

**In 2022, HDSA hosted 58 educational events** ranging from a series of hour long educational sessions for support groups to regional conferences that brought HD families together statewide. More than half were virtual offerings especially in the first six months, as many in the HD community remained cautious about gathering in groups. But the fall brought a renewed sense of normalcy and we found more events happening in person.

**This year we also saw nearly one third of the sessions hosted by an HDSA Centers of Excellence, with another third hosted by HDSA Chapters and Affiliates, and the remainder offered as special topics in an educational series hosted by support groups.** Regardless of how the educational session was offered, 2022 brought much diversity in topic and method of delivery. Our sincerest thanks, as

always, to the HDSA social workers and volunteers who spent countless hours in preparing the dynamic programming offered in 2022 and to our corporate sponsors whose funding made this program possible.

In June, HDSA took the bold step of bringing the HDSA Convention back as an in-person event after two years of virtual programming. Realizing that many might still be reluctant to travel, and mindful of the continuing health emergency that ebbed and flowed across the country, HDSA judiciously opted to cap attendance and instituted mandatory health requirements to attend, while also offering a full slate of remote sessions to compensate for the restricted attendance.

We are pleased to report that 527 HD family members, chapter leaders, exhibitors and staff were on hand to joyously open the **37<sup>th</sup> Annual Convention in Atlanta GA** while another 800 joined virtually. Over three days, HD families, near and far, heard about developments in research and clinical trials, learned about care for loved ones, and benefitted from the support of other HD families. The Convention closed with the traditional awards and candle lighting ceremony — this year as both a live and remote event! We look forward to full attendance at our 38<sup>th</sup> Annual Convention which



will be held from June 1-3 in New Orleans, LA. You can read more about the 2022 HDSA Convention in this issue of Year in Review.

In addition to family education, HDSA also continued to offer **free continuing education units to occupational therapists, social workers, and genetic counselors as well as a certificate program for physical therapists.**

As we welcome 2023, we are confident that with our extraordinary volunteers and community leaders, and the support of our corporate partners, **we will continue to offer unique educational programs to our families and healthcare professionals whatever circumstance may bring.**



**Debra Lovecky, MS**  
HDSA Director of Educational Programs  
[dlovecky@HDSA.org](mailto:dlovecky@HDSA.org)



## Research

by Kelly Andrew, BS, and Leora Fox, PhD

2022 brought scientific advances and a renewed sense of community among scientists and research advocates, as the limitations of virtual collaboration gave way to in-person connection. We marked the **10<sup>th</sup> anniversary of Enroll-HD** and families' dedication to research participation, and witnessed the launch of several new trials. HDSA remained on the pulse of HD science, sharing research news and opportunities in understandable language through our **research blog, webinars, social media, HD Trialfinder, support of HDBuzz, The Marker** research report, and **2022 Convention Research Forum**.

HDSA's research programs flourished in 2022, while past fellows continue productive scientific careers. Five budding HD scientists were awarded **Donald A. King Summer Research Fellowships**, six esteemed



researchers received **HDSA's HD Human Biology Project Fellowships**, and one early-career HD scientist was named the recipient of the competitive **2022 Berman-Topper Family Career Development Fellowship**. These 12 awards totaled over \$1.15 million committed in 2022 to HD researchers across the globe. Past and current Berman-Topper Fellows have maintained a collaborative network, and former Human Biology Project Fellows joined the next generation of independent HD scientists and mentors.

A turbulent 2021 laid the ground for new seeds to be planted in 2022 to foster the development of genetic therapies. Roche announced that despite setbacks in the development of tominersen, they would open a new trial, **GENERATION-HD2**, focused on people in earlier stages of HD. After a temporary pause to ensure participant safety, **uniQure** continues to develop the first gene therapy for HD, **AMT-130**, a one-time brain infusion. **Wave Life Sciences** also began the **SELECT-HD** trial of their next-generation HTT-lowering drug, **WVE-003**.

Also this year, the HD community saw the first oral huntingtin-lowering treatments enter clinical trials: **Novartis** launched a study of branaplam, and **PTC Therapeutics** began testing **PTC-518** in people with early HD symptoms. Unfortunately, **Novartis** announced they would end development of branaplam for HD in December due to serious side effects, but they remain committed to HD research and to sharing findings with the community.

2022 also saw the continued development of promising therapies with novel approaches to HD biology and symptoms. **Annexon** announced plans for a new trial of **ANX005**, an antibody designed to preserve brain synapses in HD. **AskBio** was approved to begin a small trial in France of a novel HD gene therapy, **BV-101**, focused on cholesterol metabolism. **Neurocrine** reported successful reduction of HD chorea in their trial of valbenazine, **KINECT-HD**. **Prilenia** fully recruited **PROOF-HD**, a large study of pridopidine for preserving total functional capacity in HD. **Sage Therapeutics** continued testing **Sage-718**, a drug targeting cognitive symptoms of HD. Dozens of other companies and hundreds of academic labs worldwide are learning more about the biology of HD and how to harness it towards treatments.



**Kelly Andrew**  
Coordinator, HDSA Research and Mission Programs  
[kandrew@HDSA.org](mailto:kandrew@HDSA.org)



**Leora Fox, PhD**  
Assistant Director, HDSA Research & Patient Engagement  
[lfox@HDSA.org](mailto:lfox@HDSA.org)

## Social Services

by Arik Johnson, PsyD

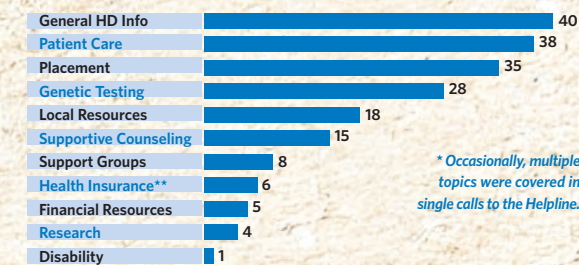
At HDSA, we strive to provide services that connect directly to people in the HD community. **HDSA Support Services** include three programs that do just that: the **HDSA Chapter and Regional Social Worker network, HDSA Support Groups**, and the **HDSA Helpline**.

Members of the **HDSA Chapter and Regional Social Worker network** are often the first contact for people living with HD. They answer helplines and emails, conduct community outreach and education, and connect with people at local and regional events. **This team of 21 social workers across the country provided over 6,200 hours of services in 2022.** A little over half of that time was spent in direct services, whether working directly with individuals and families, answering helpline calls, or leading support groups. Additionally, social workers planned events, conducted trainings, gave presentations, and developed resources for people in their communities or regions.



### Topics Addressed Through the HDSA National Helpline\*

Total Calls: 198



\*\*Includes Medicare and Medicaid inquiries

**HDSA Support Groups** continue to be a resource for people living with HD to come together to learn, share experiences, and to get support from others in the community. These groups are led by members of the HDSA Social Worker network, as well as peer facilitators from the HD community. More groups returned to in-person gatherings in 2022, and many people reported the benefit of being together again in the same room. Going to a support group is not possible for everyone, so HDSA is pleased to host 10 ongoing virtual support groups. These meetings are set up for different groups within the HD community, including: At Risk/Not Tested, HD Positive/Early Symptoms, Young Adults, Caregivers, Juvenile HD, and others. HDSA Social Workers lead these online groups and provide a space for people who may not be able to travel or who live somewhere without in-person offerings to come together.

The **HDSA Helpline (800-345-HDSA)** is a resource managed by an HDSA staff social worker who connects people to resources all across the country. People from

### Time Spent On Core Tasks by HDSA Chapter & Regional Social Workers

Total Hours: 6,204



35 states called the HDSA Helpline in 2022, with the top three states being: California, New York, and Florida. Callers ask about a wide range of topics, with the most frequent being: general HD info, patient care, placement, genetic testing, and help finding local resources. Whenever possible, people who call the HDSA Helpline are connected directly with HDSA Centers of Excellence, Social Workers, or Chapters and Affiliates in order to get the help they need closer to home.

These three programs are just part of the overall HDSA Support Services and offer a means to connect to people and resources in their own communities to help people living with HD and their families.



**Arik Johnson, PsyD**  
HDSA Chief Mission Officer  
[ajohnson@HDSA.org](mailto:ajohnson@HDSA.org)



## Disability Programs

by Allison Bartlett, Esq.

2022 was the year of the **Disability Umbrella**. HDSA's disability program expanded its disability topics and resources into the "disability umbrella" to better reflect the many facets of the disability process. Disability is more than just Social Security, it touches many areas of life, from signing up for



benefits at a first job through long-term care. Families, social workers, physicians, lawyers, and other community members have accessed resources in the expanded topic areas.

This has been the busiest year yet with 1,158 connections

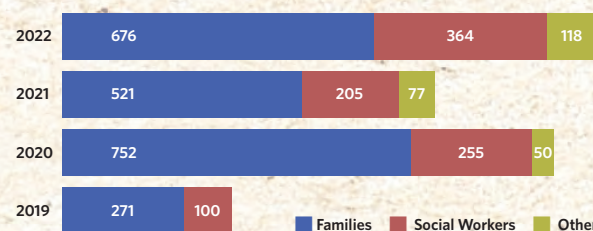
through the disability helpline, and 6,290 minutes of assistance provided to HD families.

There are many ways to interact with the disability program and access information: the **HDSA website, social media** (Facebook, Instagram, Twitter, YouTube) the **Disability Chat** webinar series and **Ask Allison!**, the disability blog introduced this year. All past webinars can be found on HDSA's Youtube page and this year Disability Chat views reached more than 10,600.

Many new resources and topics were added to the program this year, including webinars on **employment rights and accommodations, Juvenile HD and disability, and advocating for yourself**. New handouts included information on how to

### Number of Individuals Who Reached Out to HDSA for Disability Assistance

Total Individuals Served in 2022: 1,158



follow-up with Social Security, and what to expect from a Social Security medical exam. Let us know what you want to see in 2023!

**This program continues to have a truly amazing impact on the community:**

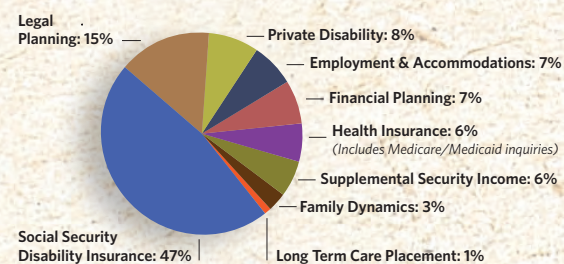
*"I cannot say enough how helpful Allison has been to me!! Allison has the perfect balance of deep and practical knowledge plus compassion. I reached out to her at each stage (including while I was making the decision when to apply). I literally do not think I could have navigated this process without her."*

*"If I did not have the access to Allison and her resources, I would not have been able to navigate the system. Not only did she provide resources but also gave me the confidence to work through the process. I am not sure how anyone would be able to do this without her support and knowledge."*

*"There's so much information to navigate through and it's nice knowing that if I need help, your resources are available to me to try and get answers."*

### Topics Addressed Through the HDSA Disability Blog, "Ask Allison!"

Total Inquiries: 604



*"Didn't have a clue until I contacted Allison. She has been there for me and family to assist in all aspects of the disability process. So thankful for you all."*

If you have questions about topics in the disability umbrella (Social Security disability, private disability or insurance, employment accommodations, health insurance — Medicare, Medicaid — financial planning, or legal planning), or have questions about the next steps in your disability journey, please do not hesitate to contact **Allison Bartlett, Esq. at 212.242.1968 ext. 218** or **abartlett@hdsa.org**. **Learn more at [HDSA.org/disability](https://www.hdsa.org/disability).**



**Allison Bartlett, Esq.**  
Senior Manager,  
HDSA Disability Programs  
[abartlett@HDSA.org](mailto:abartlett@HDSA.org)

## Youth Programs

by MaryAnn Emerick

Hesitation, fear, excitement and resilience were the feelings going into 2022. We were confident that in-person events were going to begin and continue to grow throughout the year. While virtual support groups, events, and educational series bring flexibility and accessibility of resources and support to those across the country, we knew what our community needed right now, was to be back together.

With our amazing **Youth Social Worker team** and growth of the program, we have been able to divide and conquer events around the country on different



platforms in order to provide education, support, and encourage engagement around youth and young adult topics and resources. If you have been to a **National Youth Alliance (NYA)** event and had the opportunity to meet our Youth Social Worker team, you know why this team is such an incredible asset to the NYA community.

Along with continuing our **NYA Virtual Miniseries and Support Groups**, we were able to hold three **NYA Retreats** in Pittsburgh, PA, Minneapolis, MN, and Seattle, WA! A big thank you to the local HDSA Chapters, **HDSA Social Workers**, and the local **HDSA Centers of Excellence** teams for assisting in planning and creating an unforgettable experience for our HD & JHD youth and young adult community. NYA Retreats began in 2016 to provide additional and much needed support, education, and connection within the community.

The announcement of **HDSA Convention** going back to in-person was some of the best news and our NYA board was excited to begin planning **NYA Day**, youth and young adult sessions, and create an unforgettable experience at the HDSA Convention for our community. We were able to provide scholarships to 48 NYA community members and we had over 65 people in attendance at NYA Day. The best part of Convention are the connections that are made, relationships that are formed and continue to grow, because there is no one that quite understands more than this community does. It was a long two years to make up for and it was

a weekend filled with all of needed hugs, excitement, tears, support, updates and education.

There has been great success and excitement around our partnership with **HDYO** for the **HDSA Youth and Young Adult Mentorship Program**. The Mentorship Program is to support young people across the United States who face the everyday challenges of growing up in a family affected by HD and JHD. This will provide individuals (mentees) one-on-one time with another person in the community (mentors) that have received training and have ongoing support from our Youth Social Work team. We were able to complete one virtual and one in-person mentor training in 2022! Application for both mentors and mentees remain open and we cannot wait to connect more people within our community.

In 2022, the unexpected turned into amazing experiences and community connections. We cannot wait for all of the great opportunities for our **NYA Ohana\*** in 2023!

*\* In Hawaiian, "ohana" means family — and family means nobody gets left behind or forgotten!*



**MaryAnn Emerick**  
Manager, HDSA Youth  
and Community Services  
[memerick@HDSA.org](mailto:memerick@HDSA.org)



# Please Join Us!



 Huntington's Disease Society of America

**38th ANNUAL  
HDSA  
CONVENTION**

**NEW ORLEANS**

**JUNE 1-3, 2023**

## Save the Dates!

Join us for the 38<sup>th</sup> Annual HDSA Convention  
in the Big Easy at the Sheraton New Orleans Hotel.

**JUNE 1-3, 2023, NEW ORLEANS, LA**

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 Huntington's Disease Society of America





## MISSION

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

## VISION

*A World Free of Huntington's Disease.*

## Huntington's Disease Society of America

505 Eighth Avenue, Suite 902  
New York, NY 10018

(212) 242-1968

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



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## HDSA's Family of Services

Get the help you need from the comfort and safety of your home at no cost.

- **National Helpline:** (800)-345-HDSA (4372)
- **Online Support Groups:** [HDSA.org/osg](https://HDSA.org/osg)
- **Telehealth:** [HDSA.org/telehealth](https://HDSA.org/telehealth)
- **Disability Services:** [HDSA.org/disability](https://HDSA.org/disability)
- **Clinical Trial Participation:** [HDtrialfinder.org](https://HDtrialfinder.org)
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## Highest Ratings

HDSA is an accredited non-profit with the highest ratings from the following national charity assessment organizations:

