HDSA 2022 YEAR IN REVIEW
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 37th 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. We continued to fund the 2022 Freeze HD 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 entire auction to support the HDSA mission.

In October, the 8th 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 entire 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 50,000 “HD” mentions 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
The Huntington’s Disease Society of America announced that fifty-five outstanding neurodegenerative disease care centers have been awarded the designation of HDSA Center of Excellence for 2022. In addition to the 55 grant funded sites, 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 65 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)
- Carolinas Medical 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, Seikirk 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.”

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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)
Duquesne University (NC)
Emory University (GA)
MedStar Georgetown University Hospital (DC)
Inova Health Care (VA)
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
University of Arkansas
University at Buffalo (NY)
University of California, Davis Medical Center
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 Minnesota Medical Center
University of Nebraska Medical Center
University of Pennsylvania
University of Tennessee, Health Network, Birmingham, PA*
University of Pittsburgh Medical Center (PA)
University of Rochester (NY)
University of South Carolina School of Medicine
University of South Florida
University of Southern California
University of Texas Health San Antonio
University of Utah
University of Vermont, Frederick-Bitter Center for Parkinson’s Disease and Movement Disorders
University of Virginia
University of Washington (WA)
University of Wisconsin
Vanderbilt University Medical Center (TN)
University of California, Irvine
University of Texas Medical Center
University of Tennessee, Erlanger Medical Center
Virginia Commonwealth University
Washington University
University of Medicine (MD)

University of Texas Health Science Center at Houston, McGovern Medical School*
Partner Site: Covenant Medical Group Neurology, Lubbock, TX*
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On June 9th-11th, the Huntington’s Disease Society of America hosted the 37th 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 37th 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 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 in attendance (both in-person and virtual) took part in the HDSA Convention Awards Dinner & Gala which included the annual Candle Lighting ceremony to honor the HD community.

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

HDSA National Awards
Excellence in Care
Jessica Marsolek (Minnesota)
Youth Award
Ashley Pray (Pennsylvania)
Research Award
Dr. Sarah Tabrizi (University College London)
Marjorie Guthrie Award
Heather Truogood Wilmuth (Minnesota)
Woody Guthrie Award
Kiser Carrasquillo (Massachusetts)
Person of the Year
Jessica Lou (Ohio)

HDSA plans to remove attendance restrictions and bring back popular HDSA Convention activities to the 38th Annual HDSA Convention in New Orleans, LA on June 1-3, 2023.

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 38th Annual HDSA Convention in New Orleans, LA on June 1-3, 2023.
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, neuroepigenetics, developmental neuroscience, cognitive neuroscience, computational neuroscience, and related facets of the brain and nervous system. Congratulations, Dr. Orr!

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 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.”

Charity Navigator Four-Star Rating

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. 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.

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.

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.

Dr. Harry Orr

2022 HDSA HIGHLIGHTS

HDSA Disability Chat Webinars and Disability Tips Blog

Board of Trustees Update

#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 4th against the Dallas Cowboys. Forrest is the third NFL player to lace-up for HDSA. The other two players to wear HDSA cleats during the NFL’s #MyCauseMyCleats campaign were Aaron Donald (2018) and Simi Fehoko (2021). Thank you, Forrest!

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

Forest Rhyne
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.

May: HD Awareness Month

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.

HD Hockey Classic

On May 14th, 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.

On May 5th-8th, Scott Porter hosted the second annual “HEROCLIX FOR HUNTINGTON’S” event and raised more than $26,000 to support the fight against HD!

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 Rodman some humble pie.

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.

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.
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.

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.”

Team Run for HD
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 HDSA.

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 HDSA: Envelope Blumhagen (NY), Amy Bond (CA), Craig Bond (CA), Tessa Brooks (IA), Jordan Brown (TN), Craig Calc (NY), Kerry Cavagnag (MA), Samantha Cox (IL), Andrea Dropper (WI), Haley Falkenberg (NY), Lauren Hinkley (Washington, DC), Maria Elena Hove (PA), Hannah Joach (TX), Brittni Kincaid (TX), Todd Manetotte (Wheeling, Ontario), Jessica Maranville (MN), Arturo Pardavilla III (NJ), Jeff Pazzurro (FL), Sean Bidle (CT), Jon Rink (MI), Bianca Schwarz (UT), Jaylen Sheldon (LA) and Susan Wooten (IL).

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CHICAGO MARATHON
Team Run for HD
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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 resources and services 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 the mission goals of care, cure, and community.

Learn more, visit us at HDSA.org/partnerships.

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.

#HDTV
Due to HDSA’s record-breaking awareness campaigns, we are seeing more Huntington’s disease storylines on TV shows than ever before. HDSA campaigns, we are seeing more Huntington’s disease storylines on TV shows than ever before. HDSA campaigns, we are seeing more Huntington’s disease storylines on TV shows than ever before. HDSA campaigns, we are seeing more Huntington’s disease storylines on TV shows than ever before.

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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 Lelia 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 (42nd 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 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 Eighth Annual Freeze HD Host Committee included: Layla Alizada, Dustin Brayley, Angelique Cabral, India De Beaufort, Noel Fisher, Todd Graffam, Humphrey Ray, Bruna Love, Melanie Lynskey, Kate Miner, Marianna Palka, Angel Porter, Meredith Patterson, Scott Porter, Jason Ritter, Kelly Thiebaud and Lucy Walker as well as Jessica Cain, Kipenzi Mwanaaata, Tanya Memme, Dasha Milik, Noa-Lane Noone, Patton Oswalt, Judge Reinhold, Homer Simpson, Amy Yasbeck and many more!


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2022 HDSA REGIONAL EVENTS HIGHLIGHTS

HDSA PACIFIC WEST REGION
Fairways for Hope
Rocky Mountain Chapter: $65,982
Team Hope Walk
San Diego Chapter: $44,946
Team Hope Walk San Francisco
Pacific West Region: $41,758
Team Hope Walk
Los Angeles Chapter: $36,947
Seattle Team Hope Walk
Washington Chapter: $33,333

HDSA MIDWEST REGION
Celebration of Hope
Northwest Ohio Chapter: $230,000
Ro-Prom Celebration of Hope
Wisconsin Chapter: $158,000
Chicago Celebration of Hope
Upper Great Lakes Region: $117,000
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 North East Region: $105,916
Fishy Frolic 5K & Team Hope Walk
Albany Chapter: $45,811
Jersey Shore 5K & Team Hope Walk
New Jersey Chapter: $43,634

HDSA SOUTH REGION
30th Annual HD Triathlon
South Florida Chapter: $73,415
Hope for Huntington’s
Tennasee Chapter: $28,845
Georgia Team Hope Walk
Greater North Texas Affiliate: $26,603
2023 Annual HD Triathlon
Georgia Chapter: $26,603
Georgia Team Hope Walk
Greater North Texas Affiliate: $26,603

HDSA PACIFIC WEST REGION
Alaska, Arizona, California, Colorado, Idaho, Montana, Nevada, New Mexico, Oregon, Utah, Washington, Wyoming

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

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

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

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
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 financially chartered the Act and used their voices for broader support for the legislation. Because of this, the HD Parity Act had grassroots support both in 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 grassroots email campaign during the first two weeks of December 2022. Starting with messaging to six specific states, this campaign during the first two weeks of December 2022. Starting with messaging to six specific states, this campaign covered 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 feel out the disease’s alleles. 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 driven will continue to do more.

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 HD’s dedication and commitment of the HD community and our HDSA volunteers. Though circumstance may have dictated a quick pivot from a planned in-person all volunteer 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 reaching the homes of how long educational sessions sessions for support groups to regional conferences that brought HD families together statewide. More than half were virtual and two-thirds were in-person. As the nation’s HD nonprofit, as many as the HD community members were interested in gathering online this 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 HDCA Chapter of Excellence, with another third hosted by HDCA Chapters and Affiliates, and the remainder offered as special topics in an educational series hosted by support groups. Regardless of where the educational sessions were offered, 2022 brought much diversity in topics and method of delivery. Our sincerest thanks, as always, to the HDCA 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. Reaching 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 modified mandatory health requirements to attend, while also offering a full slate of remote sessions to compensate for the restrictions allowed. We are pleased to report that 527 HD family members, chapter leaders, exhibitors, and staff were on hand to joyously open the 37th Annual Convention in Atlanta GA while another 800 joined virtually. Over three days, HD families, near and far, heard from top medical professionals whatever circumstance may bring. 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@HDUSA.org

37th Annual Convention

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Debra Lovecky, MS
HDSA Director of Educational Programs
dlovecky@HDUSA.org
2022 brought scientific advances and a renewed sense of community among scientists and research advocates, as the limitations of virtual collaboration began to ease. Authors of several new trials. HDSA remained on the pulse of HD advances and witnessed the launch of new trials. HDSA’s research programs flourished in 2022, while HDSA’s chapter and regional social worker network continued to plant new seeds to foster the development of next-generation HD therapies.

In 2022, HDSA’s research program focused on people living with HD, how to harness it towards treatments. The advancement of novel approaches to HD is supported by research report, blog, webinars, social media, HD Trialfinder, and partnership with researchers across the globe. Past and current Berman-Toppé Fellows have maintained a collaborative network, and formed a Human Biology Project Fellowship. The team of 21 social workers across the country 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.

HDSA’s social work team continued to plant new seeds to foster the development of next-generation HD therapies. HDSA’s chapter and regional social worker network, as well as peer facilitators from the HD community, continue to offer a means to connect people and resources in their own community. These three programs are just part of the overall support provided by HDSA to people living with HD and their families.

**Includes Medicare and Medicaid inquiries**

<table>
<thead>
<tr>
<th><strong>Topics Addressed Through the HDSA National Helpline</strong></th>
<th><strong>Calls: 54,055</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>General HD Info</td>
<td>20%</td>
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<tr>
<td>Individual Services</td>
<td>23%</td>
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<td>Support Groups</td>
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<td>Financial Resources</td>
<td>6%</td>
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<tr>
<td>Genetic Testing</td>
<td>8%</td>
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<tr>
<td>Event Planning</td>
<td>2%</td>
</tr>
<tr>
<td>Resource Development</td>
<td>10%</td>
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<tr>
<td>Trainings and Presentations</td>
<td>8%</td>
</tr>
<tr>
<td>Helpline</td>
<td>17%</td>
</tr>
<tr>
<td>Chart A: Time spent on core tasks by HDSA Social Services: 23% Chart B: Resources: 10% Total hours = 6203.78</td>
<td>10%</td>
</tr>
</tbody>
</table>

**Social Services**

At HDSA, we strive to provide services that connect directly to people in the HD community. HDSA Social 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 service, either working directly with individuals and families, answering helpline calls, or leading support groups. Additionally, social work events included trainings, gave presentations, and developed resources for people in their communities or work.
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 practical knowledge and empathy. I reached out to her at each stage (including while I was making the decisions when to apply). I always did think that I could have navigated this process without her.”

“So thankful for you all.”

“I have never been so passionate about something as I am about Social Security disability. 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.”

“This is the best assistant a person could hope for if they are going to apply for Social Security.”

“If I did not have the access to Allison and her resources, I have navigated this process without her.”

“I cannot say enough how helpful Allison has been to me. Allison has the perfect balance of deep practical knowledge plus compassion. I reached out to her at each stage (including while I was making the decisions when to apply). I always did think that I could have navigated this process without her.”

“This program continues to have a truly amazing impact on the community.”

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

Along with continuing our NYA Virtual (Minisessions) and Support Groups, we were able to hold three NYA Retreats in Pittsburgh, PA, Minneapolis, MN, and Seattle, WA! A leg that you to the local HDSA Chapters, NYA Social Workers, and the local NYA Centers of Excellence learn about planning and creating an unforgettable experience for our HD, JHD, and young adult communities. NYA Retreats begin in 2021 to provide additional and much needed support, education, and connection within the community.

The announcement of the 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 continued to grow, because there’s no one that quite understands more than this community does. It was a amazing way to finish up and it was a successful filled with a of relationships, excitement, tears, support, updates and education.

There has been great excitement and support around our partnerships with HDYO for our NYA Youth and Young Adult Membership Program. The Mentorship Program is to support young people across the United States who face the daily challenges of growing up in a family affected by HD and JHD. This self-paced (individual) mentorship one-on-one time with another person in the community (mentor) that has received training and is able to offer ongoing support through our Social Worker team. We were able to complete one virtual and one in-person mentor training in 2022! Application for both mentors and mentees are open and we cannot wait to connect more people within our community.

In 2023, the unexpected turned into amazing opportunities for our NYA Community. We cannot wait for all of the great opportunities, for our NYA Outreach in 2023! In Hawaiian, “ohana” means family and family means nobody gets left behind or forgotten.”

MaryAnn Emerick
Mentor- NYA Youth and Community Services memerick@HDSA.org
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JUNE 1-3, 2023, NEW ORLEANS, LA

Save the Dates!

Join us for the 38th Annual HDSA Convention in the Big Easy at the Sheraton New Orleans Hotel.
MISSION
To Improve the Lives of Everyone Affected by Huntington’s Disease and Their Families.

VISION
A World Free of Huntington’s Disease.

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
- **Telehealth:** HDSA.org/telehealth
- **Disability Services:** HDSA.org/disability
- **Clinical Trial Participation:** HDtrialfinder.org
- **Locate Resources Near You:** HDSA.org/locateresources

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