Huntington’s Disease Society of America

HDSA 2020 Year In Review
Dear Friends of HDSA,

Like you, the team at the Huntington’s Disease Society of America is ready to leave 2020 behind us and prepare for a very bright future. The COVID-19 pandemic forced us to make adjustments to everything from our everyday lives to the way we do business. Despite these extraordinary challenges, HDSA remained firmly focused on our mission to improve the lives of everyone with Huntington’s disease and their families.

Without hesitation, we transitioned from in-person events to virtual gatherings to continue to support HD families across the country in the safest and most accessible manner. Thanks to the inspiring generosity of our donors and loyal corporate partners, HDSA did not cut any of the vital support services that HD families need, especially during the pandemic.

In fact, because of COVID-19 we saw a huge increase in the use of HDSA’s online support services, such as online support groups and telerehab counseling, as well as HDSA’s nationwide network of social workers. Our website, HDSA.org, became an even more important cornerstone for families seeking information and resources, and HDSA’s library of videos and webinars grew to meet the increased demand.

In addition to our world-class support services, we continued to push HD care and research forward with direct investments to support HD clinics and science.

In early 2020, we expanded HDSA’s Center of Excellence program to a record 50 HD care teams with six satellite sites across the country. We funded four research grants under the Society’s largest research initiative, the HDSA Huntington’s Disease Human Biology Project. We also awarded Dr. Yasaman Gholamalipour from the University of Massachusetts Medical School with the prestigious Burman-Toppa Family HD Career Development Fellowship, and we named five 2020 Donald A. King Summer Research Fellowships, a vital program to train the next-generation of scientists with research expertise in Huntington’s disease.

Though we would have loved to have seen everyone in New Orleans for the 35th Annual HDSA Convention, we quickly transitioned to a completely virtual event which welcomed more than 6,200 unique viewers from 93 countries! This record-setting participation was made possible by the commitment of our speakers, exhibitors and sponsors and the dedicated volunteers who ensured that the help and hope that defines HDSA’s Conventions was preserved and expanded in this new format. Hopefully we will be able to bring Convention to Spokane, Washington in early June 2021, but regardless, robust online Convention content will be an important part of our commitment to the HD community.

Thank you for your continued support in the fight against Huntington’s disease. If 2020 taught us anything, it’s that it will take much more than a global pandemic to keep HD families from fighting for the ones they love.

Gratefully,

Louise Vetter
President & Chief Executive Officer

The critical mission work of HDSA is made possible by the fundraising of our dedicated volunteers.

We cannot thank them enough for their creativity and hard work in organizing so many creative stay-at-home events.

From scavenger hunts and wine tastings to Virtual Team Hope Walks and Celebrations of Hope, HDSA’s amazing community continued to raise much-needed funds to support our programs of education, support, advocacy and research. The virtual Sixth Annual Freeze HD event raised more than $223,000 and generated an enormous amount of awareness thanks to the work of the Freeze HD Committee.

2020 was definitely a year to put in our rear view mirror, but the challenges we faced only made us stronger. At HDSA we evolved to strengthen our connection to HD families through virtual events and resources without losing the inspiration and hope that the HDSA community provides — and requires.

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The fight against HD will not stop.
Early in the year, the Huntington’s Disease Society of America announced that fifty outstanding Huntington’s disease care facilities have been awarded the designation of HDSA Centers of Excellence for 2020. The 2020 HDSA Centers of Excellence program expanded to 50 Centers from 47 in 2019, and from just 20 in 2015. The four new Centers of Excellence are: Henry Ford Hospital (Michigan), Stony Brook University Hospital (New York), University of Kansas Medical Center, and the University of Miami (Florida). 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. 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 Florida, Kansas, Michigan, and New York, HDSA now offers care locations in 33 states plus the District of Columbia. This year, HDSA will be awarding a total of $1,550,000 to the Centers of Excellence program. To learn more about HDSA’s Centers of Excellence program please visit HDSA.org/COE.

First HD Patients Dosed In uniQure Gene Therapy Study at HDSA Center of Excellence
In June, the first two patients were dosed in the world’s first gene therapy study for HD. On June 12, uniQure announced in a press release that two brave participants had undergone the brain surgery required to deliver the experimental huntingtin-lowering therapy AMT-130. The surgeries took place at the Ohio State University’s Wexner Medical Center, which is a designated HDSA Center of Excellence. The drug is a harmless virus that contains the instructions to create a genetic weapon, a micro-RNA, that stops the huntingtin message from creating new toxic protein. This is a small and slow-moving safety trial, with 26 planned participants who will be followed closely for up to five years.

uniQure
AMT-130 is injected into the striatum, a deep part of the brain affected in the early stages of Huntington’s disease.

HDSA MILESTONE
HDSA Centers of Excellence Expand to 50 Sites

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In May, HDSA announced the recipients of the 2020 Donald A. King Summer Research Fellowships, a vital program to train the next generation of scientists with research expertise in Huntington’s disease. Huntington’s disease is a rare, hereditary neurodegenerative disorder currently affecting approximately 41,000 Americans.

The purpose of this fellowship program is two-fold: first, to attract the brightest young scientists into the field of Huntington’s disease research and second, to facilitate meaningful HD research to clarify the biological mechanisms underlying HD pathology. Applicants are evaluated by the quality of their personal academic achievements, mentoring plan, experimental design, and the feasibility of achieving their scientific goals in a short summer timeframe.

After rigorous review by the HDSA’s Scientific Advisory Board, five young scientists, the most in the history of this program, were awarded 2020 Donald A. King Summer Research Fellowships.

Sophia Friedman
Wellesley College
Sophia will complete her project at the Massachusetts Institute of Technology with David Housman, PhD, exploring genes known to alter the onset of Huntington’s disease symptoms.

Amber Keith
University of California at Irvine
Amber will be working under the guidance of Sarah Hernandez, PhD, a 2017 HDSA Berman-Topp Award recipient, in the laboratory of Dr. Leslie Thompson, to develop a model of the blood-brain barrier derived from human cells.

Tannaz Sadik
University of California at Los Angeles
Tannaz will work with Lindsay DeBiase, PhD, to study how changes in energy production affect the brain’s support cells in areas vulnerable to HD.

Kadambari Vyas
University of Central Florida
Kadambari will be mentored by former HDSA Human Biology Fellow Dr. Amber Southwell and will study aggression in mouse models of Huntington’s disease.

Melanie Alpaugh, PhD
Université Laval, Quebec City, Canada
“Interrogating Blood Samples from Huntington’s Disease Patients to Better Understand Cognitive Impairments”

Yifat Glikmann-Johnston, PhD
Monash University, Melbourne, Australia
“Targeting the Huntington’s Disease Gut Microbiome”

Simon Legan-Nia, MD
Harvard Medical School, Boston, United States
“Identifying Novel Neuroimaging Biomarkers in Early Pre-manifest Huntington’s Disease”

Björn von Essen, PhD
University Hospital Ulm, Ulm, Germany
“Feasibility of Assessing mHTT and wtHTT mRNA Levels in CSF-Derived Exosomes”

HDSA Announced Five Winners of 2020 Donald A. King Summer Research Fellowship

In December, the Huntington’s Disease Society of America announced that four research grants have been awarded under the Society’s largest research initiative, the HDSA Huntington’s Disease Human Biology Project. These grants represent HDSA’s patient-centric research focus which brings basic and clinical researchers together to facilitate Huntington’s disease science in the human condition — instead of in animal models — with the direct participation of people affected by HD.

“The HDSA HD Human Biology Project was created to enable scientists to better understand Huntington’s disease in people,” said George Yovichl, PhD, Chief Scientific and Mission Officer at HDSA. “Our 2020 fellows were selected by the Scientific Advisory Board at HDSA because their work holds the promise of filling critical gaps in our current knowledge of HD.”

HDSA received applications from researchers all around the world. Ultimately, grants were awarded to research fellows from Australia, Canada, Germany, and the United States.

At right are this year’s grant winners and project titles.

HDSA Awards Four 2020 HD Human Biology Project Fellowships
Guthrie Family Reunion
On May 29th, HDSA partnered with the Woody Guthrie Center for Woody Guthrie’s “Family Reunion” presented by Woody Guthrie Publications Inc. Woody Guthrie Publications hosted this virtual concert which raised more than $1,300 to support the fight against HD. This incredible night featured wonderful music performances from Guy Davis, Mary Gauthier, Eliza Gilkyson, Sarah Lee Guthrie, Jaimee Harris, Patterson Hood, Miner, Joel Rafael, and Marc Scibilia.

Ito Smith ‘Socks It’ to HD
Atlanta Falcons running back, Ito Smith, supported HDSA through the NFL’s #32Team32Socks campaign. The initiative invited a player from all 32 NFL teams to design a pair of socks to support their favorite nonprofit organization. Ito comes from an HD family and was eager to support the fight to end this devastating brain disorder. His socks raised $500 for HDSA. Thank you, Ito!

HDSA Introduces HDSA’s Coffee Walk
YouTube Video Series
HDSA hit the streets this year armed with a coffee and a camera to ask HD questions. You can see episodes of HDSA’s Coffee Walk at hdsa.org/coffeewalk

The Guthrie Sessions at HDSA with Clare Dunn
On July 29th, country music star Clare Dunn took part in The Guthrie Sessions at HDSA to support the fight against HD. The night featured incredible new music from Clare and she welcomed guests to a virtual backstage afterparty where she could chat with fans via Zoom. The night raised more than $1,500 for HDSA. HDSA also held two other virtual Guthrie Sessions featuring the bands BAILEN and The Barefoot Movement.

Check out The Guthrie Sessions at HDSA series at hdsa.org/guthriesessions

Founder’s Day Of Giving Raises More Than $48,000
Back for its second year, HDSA’s Founder’s Day of Giving paid tribute to our founder Marjorie Guthrie on September 18th, fifty-three years after she founded the Committee to Combat Huntington’s Disease — today’s Huntington’s Disease Society of America (HDSA). Thanks to an anonymous donor matching the gifts, the 2020 Founder’s Day of Giving raised $48,592!

Marc Scibilia Celebrates 80th Anniversary of Woody Guthrie’s This Land Is Your Land
Singer/songwriter and dear friend of HDSA, Marc Scibilia, performed a special rendition of the Woody Guthrie classic, This Land Is Your Land. This year marked the 80th anniversary of the release of HD’s coffee walk. Marc’s exclusive performance can be viewed on HDSA’s YouTube Channel.
A global audience of nearly 4,000 tuned into the Virtual 6th Annual Freeze HD event on Saturday, September 26th which raised more than $223,000 to support the fight against Huntington’s disease. Due to the COVID-19 pandemic, the Huntington’s Disease Society of America transitioned the world’s largest and most-anticipated HD fundraising event to a virtual format. Hosted live by comedian Scott Porter from a secure location in Los Angeles, Freeze HD featured an incredible online auction, live music with Brian Logan Dales from The Summer Set and dozens of videos from celebrities offering their support in the fight against HD.

“Each year, Freeze HD is star-studded call to action to stop Huntington’s disease in its tracks. While we missed gathering in person, hosting the event virtually reached the global HD community and allowed more families to connect and be inspired in this fight,” said HDSA’s President & CEO Louise Vetter. “This was a Herculean task by our event founders and the entire Host Committee, who donated their time and immense talent to make Freeze HD such a success.”

Due to the advent of the Lurie’s Chidimna and Terry Palka and featured appearances by Shailene Frieze, Wilson Bethel, Rachel Bilson, and dozens of videos from celebrities offering their support in the fight against HD.

To donate or to view the 2020 Virtual Freeze HD event, visit HDSA.org/freeze-hd.
Virtual Marathons

Stacy Coen, who comes from an HD family and is a member of the HDSA’s National Board of Trustees, did not let the COVID-19 pandemic stop her from running 26.2 miles. Although the 2020 New York City Marathon was cancelled, Stacy still raised more than $10,425 to support the fight against Huntington’s disease. Thank you Stacy!

HDSA’s ‘Team Run for HD’ raised more than $39,400 virtually at the Chicago Marathon. Thank you to HDSA’s four dedicated members: Laura Rouse, Claire Sanders, Gail Shurlow and Maddie Snowdon.

One Dime at a Time!

Michigan-native Ashley Greenway reached her goal of $10,000 by collecting soda cans throughout her community. In Michigan, each returned can is worth ten cents. She collected cans throughout the year from her entire town. She would do pick-ups from neighbors and friends almost every day. Quick math says she collected 100,000 cans!

HDSA Board of Trustees

Dr. Victor Sung has seamlessly stepped into his new role as Chair of HDSA’s National Board of Trustees after E.J. Garmer served her two-year term. HDSA thanks E.J. for her amazing work as Chair as well as Dr. Don Higgins, Dr. Arik Johnson, and Dav Vandersloot who have also finished their term on HDSA’s Board of Trustees. HDSA welcomes new Board members Angela Allen, Mark Coe, Dr. Erin Furr-Stimming, Kelsey Porter and Dominique Thomas.

This Week in HD Research

HDSA’s Dr. Leora Fox keeps you up to date each week with the This Week in HD Research blog. Get the latest in HD research news by visiting HDSA.org/blog.

Dr. Leora Fox, HDSA Assistant Director, Research and Patient Engagement

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NYA Adopts a New Logo

This year, HDSA’s National Youth Alliance (NYA) received a makeover with a new logo as this inspiring group continues their mission to improve the lives of young people affected by HD and their families.

Learn more about HDSA’s National Youth Alliance by visiting HDSA.org/NYA.

#GivingTuesday

Thanks to the generosity of the HD community, more than $146,500 was donated to support HDSA’s fight against Huntington’s disease during the two #GivingTuesday initiatives in 2020. #GivingTuesdayNow in May raised $73,000 while #GivingTuesday in December garnered more than $73,500!

Additionally, HDSA staff members Allison Bartlett, Deb Boyd, Chris Cosentino, Jermion Skals and Louise Vetter represented TEAM HDSA during the Global Gateway Advisors Charity Trivia Night on #GivingTuesday in December. The team was crowned the tournament champion and won $4,700 for HDSA!

Get the latest news by following HDSA’s social media channels!

Facebook: facebook.com/HDSofA
Twitter: twitter.com/HDSA
Instagram: instagram.com/HDSAnational/
YouTube: hdsa.org/youtube
LinkedIn: linkedin.com/company/huntingtons-disease-society-of-america/
2020 REGIONAL EVENT HIGHLIGHTS

Every year, HDSA’s 50+ Chapters and Affiliates host more than 300 events across the country thanks to the amazing leadership of HD families and volunteers. Here are just a few!

**PACIFIC REGION**
(Washington, Oregon, California, Montana, Idaho, Wyoming, Nevada, Utah, Arizona)
San Diego Team Hope Scavenger Hunt
San Diego Chapter
$62,136

Los Angeles Team Hope Walk
Los Angeles Chapter
$40,000

**WESTERN WASHINGTON**
Team Hope Walk
Washington Chapter
$32,180

**NEW YORK / NEW JERSEY REGION**
(New York, New Jersey)
NYC Team Hope Walk
NYC Chapter
$104,600

New Jersey Team Hope Walk
New Jersey Chapter
$39,122

**SOUTHEAST REGION**
(Tennessee, Alabama, North Carolina, South Carolina, Georgia, Florida)
South Florida Triathlon
South Florida Chapter
$51,685

Atlanta Celebration of Hope
Great Lakes Region
$72,672

**GREAT LAKES REGION**
(Wisconsin, Michigan, Illinois, Indiana, Ohio, Missouri, Kentucky)
Naperville Team Hope Walk
Naperville Chapter
$115,450

Chicago Celebration of Hope
Great Lakes Region
$72,672

**NEW ENGLAND REGION**
(Vermont, New Hampshire, Maine, Massachusetts, Rhode Island, Connecticut)
Naperville Team Hope Walk
Naperville Chapter
$115,450

**Huntington’s Disease Society of America**

Full story online at huntington.org/events/2020-
regional-event-highlights

Special thanks to our National Team Hope Sponsors

Genentech
A Member of the Roche Group

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**MID-ATLANTIC REGION**
(District of Columbia, Delaware, Maryland, Virginia, West Virginia, Pennsylvania)
Worx Warrior
Virginia PA Chapter
$10,977

Fast Track
Virginia PA Chapter
$1,989

**UPPER MIDWEST REGION**
(North Dakota, South Dakota, Nebraska, Minnesota, Iowa)
South Dakota Team Hope Walk
South Dakota Chapter
$22,580

Cruisin’ for a Cure
Iowa Chapter
$16,598

Minneapolis Team Hope Walk
Minneapolis Chapter
$15,937

**SOUTH CENTRAL REGION**
(Colorado, Kansas, New Mexico, Oklahoma, Texas, Arkansas, Louisiana, Mississippi)
The Great Texas Team Hope Walk
South Central Region
$37,581

**SOUTHEAST REGION**
(Georgia, South Carolina, North Carolina, Tennessee, Florida, Alabama)
South Florida Triathlon
South Florida Chapter
$91,650

Atlanta Team Hope Walk
Georgia Chapter
$29,837

South Carolina Team Hope Walk
South Carolina Chapter
$6,718

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Disease Society of America transitioned the 35th Annual HDSA Convention, which was scheduled to be in New Orleans, into a virtual event on June 4-7, 2020. In addition to overcoming the challenges of the pandemic, the unique virtual event allowed guests who might not otherwise have been able to travel to New Orleans due to health and expense to opportunity to attend sessions.

HDSA scheduled forty sessions over the four-day expense to opportunity to attend sessions. More than 1,500 unique email registrants and 93 nations around the world participated in the global online experience. “Honestly, it never occurred to us not to hold Convention this year,” said Louise Vetter, HDSA’s President & Chief Executive Officer. “When COVID-19 made New Orleans travel impossible, our focus shifted to creating a virtual event that included world-class presentations without losing the extraordinary connection and emotion which the HDSA Convention is known for each year.”

The Virtual Convention featured nearly all of the regularly scheduled Convention programming with some surprise special guests. The Welcome Reception on Thursday included a virtual concert featuring performances by Marc Scibilia, The Mammals and Dave Hause. Marc Scibilia paid tribute to the 80th Anniversary of Woody Guthrie’s “This Land Is Your Land” with his beautiful acoustic rendition of the iconic song.

On Friday, the education and support sessions began and included all the popular presenters normally seen at an HDSA Convention. Dr. Ed Wild and Dr. Jeff Carroll from HDBuzz.net delivered yet another entertaining and very informative “Ask the Scientists Anything” session. The virtual workshop was so successful that HDSA and HDBuzz will produce more throughout the year on a regular basis. Friday night was capped off with the NYA Talent Show hosted by Jennifer Simpson, LCSW and Katie Moer.

On Saturday, HDSA’s Chief Scientific and Mission Officer, Dr. George Yehling hosted the Research Forum which included updates from Annese Biosciences, Wave Life Sciences, Roche/GeneTec, HDBuzz and a Clinical Trials Showcase featuring CHDI Foundation, uniQure, Triplet Therapeutics and Neurocrine Biosciences.

On the fourth and final day of the Virtual Convention, more sessions and support groups were conducted with incredible attendance numbers. The Virtual Convention Closing Ceremony program on Sunday night revealed that Spokane, Washington will be the site for the 36th Annual HDSA Convention location in 2021. The culminating event was the presentation of HDSA’s National Awards to HDSA South Carolina Affiliate (Chapter of the Year), Autumn Furioso (Truth/HD Award), Massachusetts & Rhode Island Chapter (Chapter of the Year) and Jennifer Brown (Person of the Year). Marjorie & Woody Guthrie’s daughter, Nora Guthrie made a surprise appearance to present Bill Kline with the Woody Guthrie Award and Jack Griffin with the Marjorie Guthrie Award. The Closing Ceremony concluded with the emotional Grand Illumination Ceremony where HDSA recognized the entire HD Community and then a fun-filled virtual dance party.

Throughout the four-day Virtual Convention attendees had the opportunity to connect on the HDSA Convention app, as well as visit the Virtual Exhibit Hall.

Thank you to everyone who attended and supported the 35th Annual HDSA Convention! We look forward to seeing you in Spokane, Washington next year on June 10-12, 2021!

To view all recorded Convention sessions, please visit HDSA.org/convention

Thank you to our generous sponsors that made the 35th Annual HDSA Convention possible!
Anne Leserman Retires From HDSA

After 17 years of tireless work on behalf of HD families while at HDSA and the HDSA Center of Excellence at the University of Iowa, HDSA’s Assistant Director of Community Services, Anne Leserman, retired on September 3, 2020.

Anne joined HDSA in 2012 as Manager of Community Services and Mid-Atlantic Regional Social Workers. Most recently, as the Assistant Director of Community Services, Anne had the critical mission of managing the Social Worker and Support Group network nationwide. This involved managing 70 social workers at HDSA Centers of Excellence locations, Chapters, and Affiliates as well as advising more than 150 Support Groups. Anne also provided counseling and resources for HD professionals and families overseeing HDSA’s national helpline and professional training programs. She also spearheaded HDSA’s free telehealth service in partnership with AmWell.

In honor of her dedication to the Huntington’s disease community, Anne was recognized with the Patient and Family Service Award at HDSA’s Annual Convention in 2011.

Anne intends to spend more time in Seattle, Washington with her family and new puppy, Gracie. Her colleagues at the national HDSA office will miss her sage advice, sarcastic wit, and wonderful baking.

HDSA's Here’s The Deal, is a web series hosted by Jennifer Simpson, LCSW that features in-depth conversations on important HD topics to assist viewers in dealing with the many aspects of HD. Watch Here’s The Deal at HDSA.org/heresthedeal.

HDSA & Me Webinar Series


HDSA & Me is a virtual educational series for the HD community which features experts presenting a wide range of HD-related topics. The series aims to educate, engage, and empower those who are affected by HD or wish to learn more.

You can view the virtual educational series ‘HDSA & Me’ at HDSA.org/hmsa-me.

MAY

#LetsTalkAboutHD

HDSA kicked off Huntington’s Disease Awareness Month in May with a Virtual Team Hope Walk event. During HD Awareness Month, several celebrities, athletes, musicians, and influencers used their platforms to raise much-needed awareness by participating in the #LetsTalkAboutHD campaign. Some notable new supporters included stars of All Elite Wrestling (AEW) including Brandi Rhodes, AEW’s Chief Brand Officer; actor Patrick Warburton (Seinfeld, Family Guy); rock musician Brett Scallions and many more.

Supporters from across the globe came together to recognize HD Awareness Month. On May 15th, HDSA collaborated with multiple international HD organizations to celebrate International HD Awareness Day. The #LetsTalkAboutHD videos can be seen on HDSA’s YouTube Channel at HDSA.org/youtube.
The COVID-19 pandemic has affected all aspects of our society, and the HD research community was not immune to the consequences of this virus. HD laboratory research and clinical trials were delayed to curb the spread of the virus, but the HD community did what it always does… adapt and persevere. We came together quickly to reimagine our New Orleans Convention as a virtual event that safely reached more than 1,500 people in over 90 countries. It was here that families got firsthand updates from scientists and clinicians from around the globe on our collective progress since we last met in Boston. Despite the setbacks 2020 presented, this year marked several notable events in the history of HD research.

**uniQure** dosed the very first US patients with an experimental HD gene therapy that could permanently reduce harmful huntingtin protein with just one dose.

**Novartis** announced plans to test an orally administered drug to lower huntingtin, and **PTC Therapeutics** is traveling a similar path.

**Triplet Therapeutics** fully recruited SHIELD-HD with the goal of understanding and ultimately preventing CAG repeat expansion, and **Azevan** reported clinical trial data suggesting that their drug SRX-246 may improve irritability and aggression in HD patients.

While 2020 will undoubtedly go down in history as one of the most challenging years ever, it will also be remembered as a year of incredible expansion of our HD drug pipeline, based on solid science from observations in humans. While we anxiously await results from the current huntingtin lowering trials like Roche’s Generation-HD1 and Wave’s Precursor-HD1, there is more excitement and hope than ever due to the depth and diversity of our clinical trial bench. Here’s to a safe and happier 2021 with continued progress towards a world free of HD!

**GEORGE YOHRLING, Ph.D.** is HDSA’s Chief Scientific Officer and Chief Mission Officer. gyohrling@HDSA.org

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**RESEARCH**

BY GEORGE YOHRLING, Ph.D.

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**ADVOCACY**

BY JENNIFER SIMPSON, LCSW

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2020 was a year full of hectic disruptions in government and governmental processes, but also amazing opportunities. HDSA joined in with our partners in the healthcare space to advocate for the inclusion of expanded FMLA benefits for caregivers of high-risk individuals during the COVID-19 crisis. HDSA was committed to keeping our community informed of the impacts and risks of COVID-19 for HD families, providing resources like HDASA’s video series Here’s the Deal that featured interviews with Dr. Arik Johnson and Dr. Victor Sung, infographics on COVID-19 relief packages and how the HD community can benefit, and more.

We also pushed for the HD Parity Act during the pandemic, setting up virtual meetings with community members and our HDSA advocacy team in order to best explain what and why the HD Parity Act is so important. We will have virtual “fly-ins” and make sure all members of Congress know what the HD Parity Act is, how crucial immediate care is for our community, and how impactful their support is for their constituents.

We will never stop fighting and finding ways to have our small but mighty community be heard. We know we can pass this bill, we’ve seen it happen in 2020 for our partners in the ALS community with a second waiver of the 5-month waiting period for monetary SSDI benefits. Now, it’s our turn.

Learn more at HDSA.org/takeaction

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**JENNIFER SIMPSON, LCSW** is HDSA’s Assistant Director of Youth & Community Services. jsimpson@HDSA.org

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HDSA’s mission is to ensure that all people affected by HD are provided with the care and support they need, wherever they are. HDSA’s vision is a world in which the HD Parity Act is law, providing coverage for care and treatment of HD symptoms and complications.
HDSA, in partnership with the National Society of Genetic Counselors (NSGC), launched a new continuing education program in April on the NSGC website. This new three-year CE course offers genetic counselors across the United States the opportunity to learn about the unique issues surrounding both presymptomatic and symptomatic genetic testing for Huntington’s disease. The course requires four CE units. From April through the end of November the course attracted more than 900 participants with more than 400 CE units awarded to genetic counselors who successfully completed all five modules in the course.

HDSA also relaunched its joint course with the American Occupational Therapy Association (AOTA) for occupational therapy providers. During the first six months, AOTA awarded 43 CE hours to occupational therapists. Even as 2020 challenged the way that HDSA offered education to our families and our healthcare professionals, the Society responded by expanding its use of online tools in order to provide both live and recorded content for our many stakeholder groups. This new three-year CE course was successful, we will continue to develop more top-notch courses and focus groups and HDSA Centers of Excellence quickly re-grouped and, by the latter half of 2020, had begun to offer virtual educational events. As we entered the year, HDSA will have presented diverse educational programming through seven in-person, pre-pandemic and 10 virtual educational events for a total of 36 unique offerings. Compared to 2019, when HDSA hosted 10 educational days, this is a testament to the dedication and commitment of our volunteers and leadership who worked very hard to provide not only compelling programming but also a sense of connection during these challenging times.

In like manner, our Chapters, Affiliates, support groups and HDSA Centers of Excellence quickly re-grouped and, by the latter half of 2020, had begun to offer virtual educational events. As we entered the year, HDSA will have presented diverse educational programming through seven in-person, pre-pandemic and 10 virtual educational events for a total of 36 unique offerings. Compared to 2019, when HDSA hosted 10 educational days, this is a testament to the dedication and commitment of our volunteers and leadership who worked very hard to provide not only compelling programming but also a sense of connection during these challenging times. 

HDSA & Me, a new hour-long family-focused web series that continued our family-focused web series that continued our educational initiatives. HDSA & Me began in April as a weekly series of activities and speakers that addressed issues of isolation, caregiver stress, and limited outside engagement by bringing armchair experts, disease professionals, the Society responded by expanding its use of online tools in order to provide both live and recorded content for our many stakeholder groups. This new three-year CE course was successful, we will continue to develop more top-notch courses and focus groups and HDSA Centers of Excellence quickly re-grouped and, by the latter half of 2020, had begun to offer virtual educational events. As we entered the year, HDSA will have presented diverse educational programming through seven in-person, pre-pandemic and 10 virtual educational events for a total of 36 unique offerings. Compared to 2019, when HDSA hosted 10 educational days, this is a testament to the dedication and commitment of our volunteers and leadership who worked very hard to provide not only compelling programming but also a sense of connection during these challenging times.

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HDSA & Me, a new virtual educational series for the HD community

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HDSA & Me, a new virtual educational series for the HD community

educate. engage. empower.

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Ask Allison!

Many families and professionals ask HDSA’s disability expert Allison Bartlett questions about the disability process, health insurance, private disability, legal planning, and locating disability resources in their community. We even added the ‘Ask Allison!’ section to the website to easily contact her.

2020 has been a busy year for the HDSA disability program thanks to all of your questions. We have provided disability assistance, resources, and consultations to more than 1000 requests from social workers and families via phone and email, more than double from 2019! While travel was not an option this year, Allison was able to present at HDSA’s Virtual Convention and she spoke at numerous virtual education days and virtual support groups across the country, which has been a great resource for families – she is available to speak at virtual events in 2021.

HDSA maintains a roster of 25 professional and regional social workers, with the reboarding of veteran workers into new positions including Eastern Washington state and other areas where chapters and affiliates had worked hard to make those supports available to their communities. HDSA grew our online telehealth program, seeing increases in usage throughout 2020 of our AmWell counseling program as well as growth in national online support groups. We expanded our internal support group offerings to include groups for young adults, family planning and beginning your HD journey.

HDSA also began a process of reviewing our national youth support group program, with the goal of providing additional support and structure to our group leaders in 2021. We are thrilled to see our support network growing across the country, especially during a pandemic when folks have needed help more than ever, and look forward to seeing them grow even more by 2021.

Learn more at HDSA.org/support

Jennifer Simpson
Assistant Director of Youth & Community Services
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BY ALLISON BARTLETT, ESQ.
DISABILITY PROGRAMS

If you have questions about Social Security disability or general disability topics, please contact Allison Bartlett, Esq. at (212) 242-1968, ext. 218 or abartlett@hdsa.org. Learn more at HDSA.org/disability.

BY JENNIFER SIMPSON, LCSW
SUPPORT & SERVICES

HDSA expanded online support group offerings to include groups for young adults, family planning.

If you have questions about Social Security disability or general disability topics, please contact Allison Bartlett, Esq. at (212) 242-1968, ext. 218 or abartlett@hdsa.org. Learn more at HDSA.org/disability.

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SUPPORT & SERVICES

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MISSION
To improve the lives of everyone affected by Huntington’s Disease and their families.

VISION
A World Free of Huntington’s Disease.

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PLEASE NOTE: Our ability to host the 36th Annual HDSA Convention in Spokane is dependent on federal, state, and local public health guidelines. Please check www.HDSA.org regularly for updated information. Thank you!