



# HDSA 2020 Year In Review



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# 2020 WAS TOUGH, BUT...

# THE FIGHT AGAINST HD WILL NOT STOP

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 free online support services, such as **online support groups** and **telehealth 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 webinars and video resources 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 **Berman-Topper 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.

Although we would have loved to have seen everyone in New Orleans for the 35<sup>th</sup> Annual HDSA Convention, **we quickly transitioned to a completely virtual event which welcomed more than 6,200 live 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.

**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.

**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



# HDSA CENTERS OF EXCELLENCE



## HDSA Centers of Excellence Expands to 50 Sites

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](https://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 19<sup>th</sup>, 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.



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

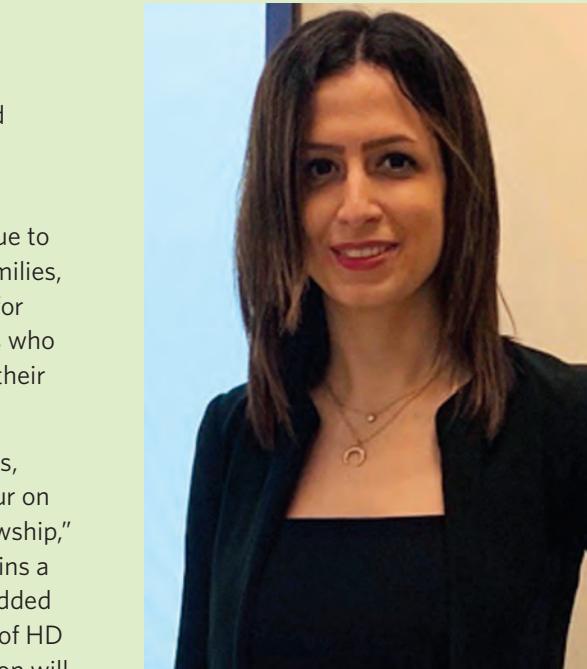
# RESEARCH FUNDING

## 2020 Berman-Topper Family HD Career Development Fellowship

In May, HDSA announced that **Dr. Yasaman Gholamalipour** from the University of Massachusetts Medical School was awarded the **2020 HDSA Berman-Topper Family HD Career Development Fellowship**.

This prestigious fellowship, made possible due to the generosity of the **Berman** and **Topper** families, provides up to \$80,000 of funding per year for three years to young scientists and clinicians who desire to make Huntington's disease part of their long-term career plan.

"On behalf of the Topper and Berman families, I would like to congratulate Dr. Gholamalipour on being named the 2020 recipient of this fellowship," said **Michael Berman**. "Dr. Gholamalipour joins a terrific group of young scientists who have added both knowledge and enthusiasm to the field of HD research, and we are sure that her contribution will be significant."



Dr. Yasaman Gholamalipour

**2016** Dr. Ricardo Mouro-Pinto, Massachusetts General Hospital

**2017** Dr. Tamara Mauri, McMaster University  
Dr. Sarah Hernandez, University of California at Irvine

**2018** Dr. Rachel Harding, University of Toronto

**2019** Dr. Lauren Byrne, University College London  
Dr. Nicholas Caron, University of British Columbia

**Previous Recipients of the Berman-Topper HD Career Development Fellowship**

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

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



**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.



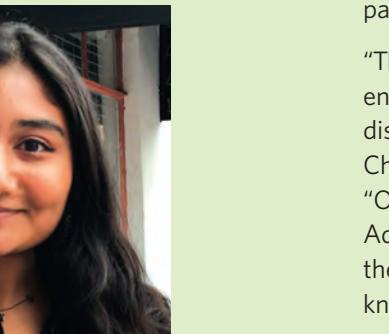
**Amber Keith**  
*University of California at Irvine*  
Amber will be working under the guidance of **Sarah Hernandez, PhD**, a 2017 HDSA Berman-Topper Career Development Fellowship recipient, in the laboratory of **Dr. Leslie Thompson**, to develop a model of the blood-brain barrier derived from human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



**Lav Patel**  
*Ohio State University*  
Lav will spend time in the lab of **Richard Fishel, PhD**, to visualize DNA repair proteins that affect the expansion of CAG repeats.



**Tasneem Sadok**  
*University of California at Los Angeles*  
Tasneem 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.

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.

## HDSA Awards Four 2020 HD Human Biology Project Fellowships

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 Yohrling, 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.



**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 Laganiere, MD**  
*Harvard Medical School, Boston, United States*

*"Identifying Novel Neuroimaging Biomarkers in Early Pre-Manifest Huntington's Disease"*



**Bjoern von Einem, PhD**  
*University Hospital Ulm, Ulm, Germany*

*"Feasibility of Assessing mHTT and wtHTT mRNA Levels in CSF-Derived Exosomes"*

# 2020 HIGHLIGHTS



## ABC News Story on Huntington's Disease

On July 3<sup>rd</sup>, **ABC News** collaborated with HDSA to produce a powerful story on Huntington's disease.

The 16-minute segment featured ABC News' anchor **Linsey Davis** following two families grappling with the rare genetic disorder.

You can see this video at [HDSA.org/abcnews20](https://www.hdsa.org/abcnews20)

AT LEFT: Scott and Kelsey Porter discuss HD's impact during an ABC News feature.

## 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. Ito's socks raised \$500 for HDSA.

Thank you Ito!



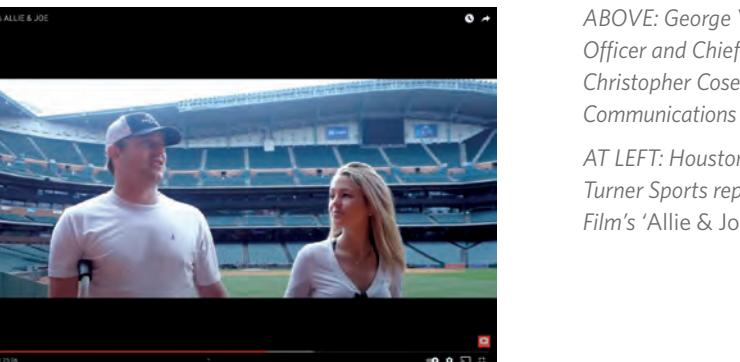
Ito Smith

## HDSA Films Presents Allie & Joe

**HDSA Films** present a powerful short film about sports reporter Allie LaForce and major league pitcher Joe Smith.

The couple discuss Huntington's disease and their journey through PGD-IVF to have an HD-free child.

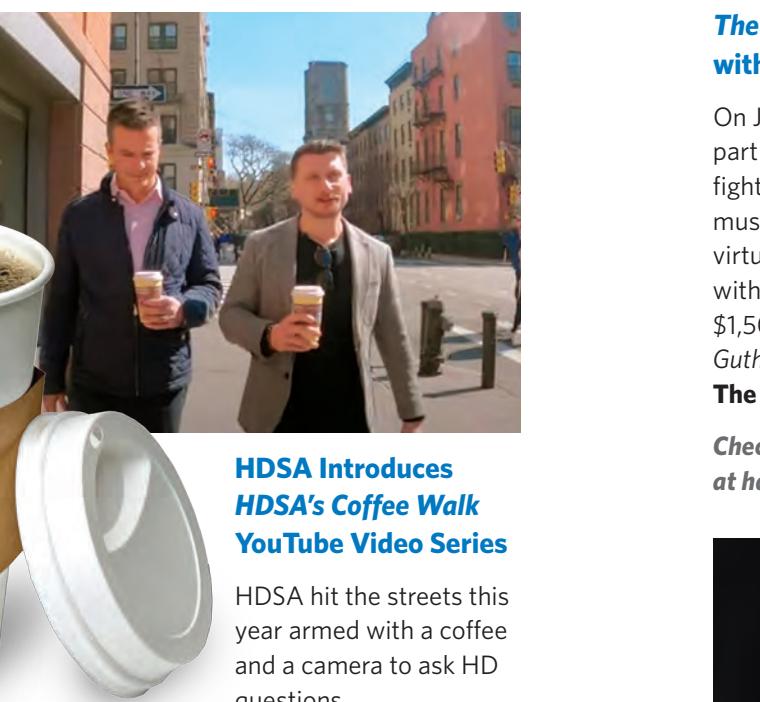
Watch the film at [HDSA.org/allieandjoe](https://www.hdsa.org/allieandjoe)



ABOVE: George Yohrling, PhD, HDSA's Chief Scientific Officer and Chief Mission Officer (at left) chats with Christopher Cosentino, HDSA's Director, Marketing and Communications in an episode of HDSA's Coffee Walk.

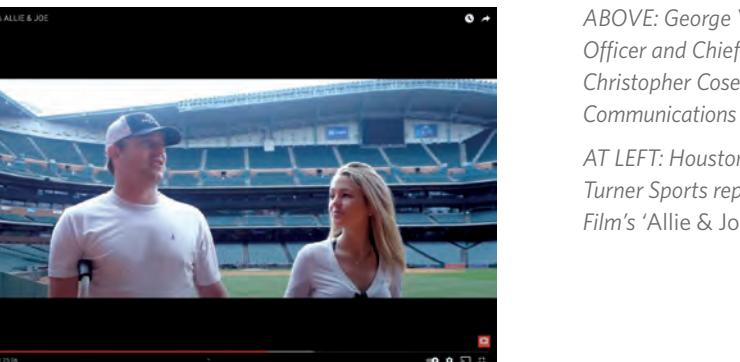
AT LEFT: Houston Astros' pitcher Joe Smith with his wife, Turner Sports reporter Allie LaForce in a scene from HDSA Film's 'Allie & Joe'.

## HDSA Introduces HDSA's Coffee Walk YouTube Video Series



You can see episodes of HDSA's Coffee Walk at [HDSA.org/coffeewalk](https://www.hdsa.org/coffeewalk)

Watch the film at [HDSA.org/allieandjoe](https://www.hdsa.org/allieandjoe)



ABOVE: George Yohrling, PhD, HDSA's Chief Scientific Officer and Chief Mission Officer (at left) chats with Christopher Cosentino, HDSA's Director, Marketing and Communications in an episode of HDSA's Coffee Walk.

AT LEFT: Houston Astros' pitcher Joe Smith with his wife, Turner Sports reporter Allie LaForce in a scene from HDSA Film's 'Allie & Joe'.

## The Guthrie Sessions at HDSA with Clare Dunn

On July 21<sup>st</sup>, 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 \$1,300 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**.

Check out The Guthrie Sessions at HDSA series at [hdsa.org/guthriesessions](https://www.hdsa.org/guthriesessions)



Clare Dunn

## Guthrie Family Reunion

On May 28<sup>th</sup> 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**.



Woody Guthrie

## 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 18<sup>th</sup>, 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!



Marjorie Guthrie

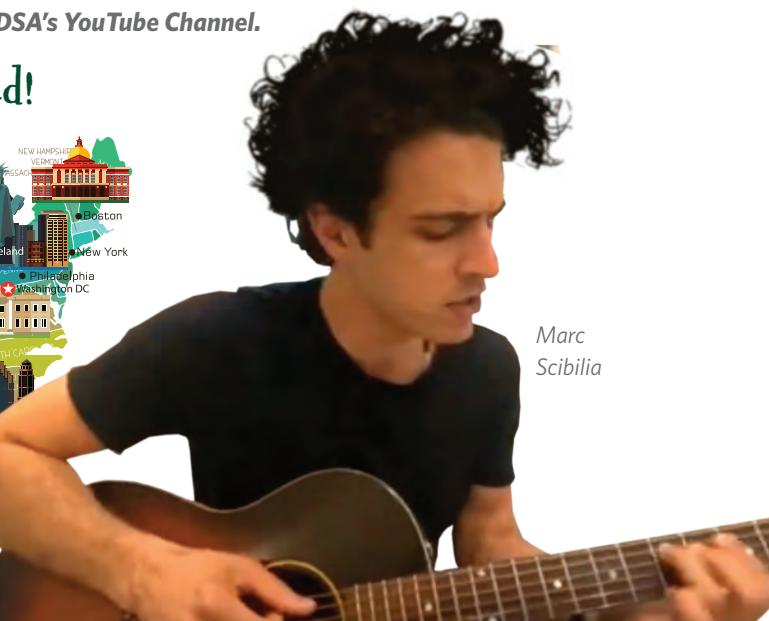
## Marc Scibilia Celebrates 80<sup>th</sup> Anniversary of Woody Guthrie's *This Land Is Your Land*

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 80<sup>th</sup> anniversary of the release of this iconic song.

Marc's exclusive performance can be viewed on HDSA's YouTube Channel.



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Marc Scibilia

## **Virtual Sixth Annual Freeze HD Event Raises More Than \$223,000 for HDSA**

**A global audience of nearly 4,000 tuned into the Virtual 6<sup>th</sup> Annual Freeze HD event on Saturday, September 26<sup>th</sup> 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 actor **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 host **Scott Porter**, event founders **Marianna Palka** and **Jason Ritter**, and the entire **Host Committee**, who donated their time and immense talent to make Freeze HD such a success."

The event honored the lives of **Hurumia Chidinma** and **Terry Palka** and featured appearances by **Shakira Barrera**, **Wilson Bethel**, **Rachel Bilson**, **Alison Brie**, **India De Beaufort**, **Tom Ellis**, **Noel Fisher**, **Courtney Friel**, **Neil Gaiman**, **Kimmy Gatewood**, **Seth Green**, **Rebekka Johnson**, **Bryce Dallas Howard**, **Allie LaForce**, **Rachel McAdams**, **Kate Miner**, **Jaylen Moore**, **Lamorne Morris**,

**Marianna Palka**, **Gayle Rankin**, **Jason Ritter**, **Joe Smith**, **Rod Man**, **Britney Young** and many more. There were also extraordinary music performances by **Zac Barnett**, **Shoshana Bean**, **Brian Logan Dales**, **Leslie Powell**, **The Edge Effect** and **Tyson Ritter**.

The bidding in the **Virtual Auction** was fierce up until the last second. 2,037 bids were placed throughout the evening on more than 100 auction items, but the most coveted was a *Supernatural* television series memorabilia package donated by **Jared Padalecki** that garnered 193 bids!

Immediately following the Freeze HD program, guests who donated at least \$50.00 were invited to an exclusive **VIP Afterparty** hosted by comedian **Rod Man**. The hour-long Zoom event featured an opportunity to meet **Kate Miner**, **Marianna Palka**, **Scott Porter** and **Jason Ritter**, as well as take part in a fun **trivia game** that gave away a \$100 Amazon gift card to the winner.

**Thank you to the Freeze HD Host Committee:**  
**Angelique Cabral**, **Jessica Cain**, **Kipenzi Chidinma**, **Chris & Lisa Davis**, **Brian Logan Dales**, **Blake & Jenne Coler-Dark**, **Jessica Etting**, **Matt & Courtney Hamilton**, **Gentille Koosed**, **Jaylen Moore & Britt Logan**, **Justin & Kate Miner**, **Elliott & Tracy Owen**, **Kelsey Porter**, **Carly Ritter**, **Nancy Morgan Ritter**, **Tyler & Lelia Ritter**, **Emily & Jamie Rodgers**, **Alana Yankowitz** and **Jason Ziven**.

To donate or to view the 2020 Virtual Freeze HD event, visit [HDSA.org/freeze-hd](https://HDSA.org/freeze-hd)

### **Thank You to Our Generous Sponsors!**

#### **GOLD SPONSORS**

- Genentech
- Neurocrine
- uniQure

#### **SILVER SPONSORS**

- Bel Aire Internet
- Marron Foods
- Wave Life Sciences

#### **BRONZE SPONSORS**

- Fake Empire
- Keyes Real Estate
- Temple Hill Productions

#### **BAR SPONSORS**

- After Hours Theatre Company
- Jessica & Tammy Cain
- Phil & Tamar Koosed
- Netflix
- Twelve Rivers Realty
- Warner Brothers

#### **FRIEND SPONSORS**

- Brillstein Entertainment Partners
- Blake & Jenne Coler-Dark
- Fidelity National Title
- NRE Commercial Real Estate
- Carly Ritter



1. Thank you to our generous sponsors! 2. HDSA President & C.E.O., Louise Vetter 3. Zac Barnett performs 4. Virtual Freeze HD host Scott Porter with auction items display 5. Jason Ritter 6. Marianna Palka 7. Alison Brie 8. Scott Porter joins Brian Logan Dales and guitarist, Matt Beckley in song 9. Tyson Ritter sings 10. Kate Miner 11. Last year's Freeze HD host, actor and comedian Lamorne Morris, checks in 12. Seth Green 13. Rachel McAdams 14. Tom Ellis 15. Kipenzi and Majrjani Chidinma 16. Scott and Kelsey Porter with children — all part of the HDSA family! 17. Scott Porter joins the acapella group, *The Edge Effect*, in a rousing rendition of the Beatles' classic, *Come Together*.



### 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!

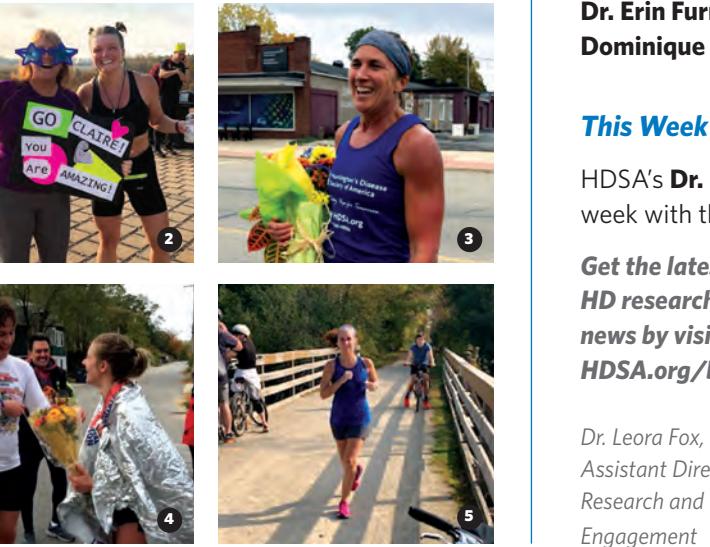
AT LEFT: Ashley Greenway and family.

### 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**.

1. Stacy Coen (inset) strikes a strong "Cure HD" pose before her run. 2. Claire Sanders (r.) with supporter. 3. Gail Shurlow receives kudos at the end of her run. 4. Maddie Snowdon is presented with congratulatory flowers. 5. Laura Rouse shows her winning form.



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### 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. Garner** 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 Dan Vandivort** who have also

finished their time on HDSA's Board of Trustees. HDSA welcomes new Board members **Angela Allen, Mark Coe, Dr. Erin Furr-Stimming, Kelsey Porter and Dominique Thomas**.



Dr. Victor Sung, Chair of HDSA's Board of Trustees

### 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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### #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, Jamison Skala 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 **\$4,750** for HDSA!

**GIVING TUESDAYS  
OVER  
\$146,500  
RAISED FOR HDSA**



### Journalist Yousef Gamal El-Din Supports HDSA

Prominent international journalist **Yousef Gamal El-Din** comes from an HD family and his mother passed away from the disease after a brave 20 year battle. In December, Yousef shared an inspiring PSA supporting HDSA and encouraging folks around the world to join the fight against Huntington's disease.

You can view **#LetsTalkAboutHD** with Yousef Gamal El-Din on HDSA's YouTube channel.

### NYA Adopts a New Logo

This year, HDSA's **National Youth Alliance (NYA)** received a makeover with a new logo as this inspiring group continued 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](#).



### HDSA Social Media

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

- **Facebook:** [facebook.com/HDSofA](https://facebook.com/HDSofA)
- **Twitter:** [twitter.com/HDSA](https://twitter.com/HDSA)
- **Instagram:** [instagram.com/HDSAnational/](https://instagram.com/HDSAnational/)
- **YouTube:** [hdsa.org/youtube](https://hdsa.org/youtube)
- **LinkedIn:** [linkedin.com/company/huntington-s-disease-society-of-america/](https://linkedin.com/company/huntington-s-disease-society-of-america/)

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# 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!

Special thanks to our National Team Hope Sponsors

**Genentech**  
A Member of the Roche Group

**teva**



## SOUTH CENTRAL REGION

(Colorado, Kansas, New Mexico, Oklahoma, Texas, Arkansas, Louisiana, Mississippi)

**The Great Texas Team Hope Walk**  
South Central Region  
\$37,581

**16<sup>th</sup> Annual Hero's vs. Villains Virtual Run & Walk**  
Rocky Mountain Chapter  
\$26,747

**6<sup>th</sup> Annual Fairways for Hope Golf Event**  
Rocky Mountain Chapter  
\$11,292



## UPPER MIDWEST REGION

(North Dakota, South Dakota, Nebraska, Minnesota, Iowa)

**South Dakota Team Hope Walk**  
South Dakota Chapter  
\$22,500

**Cruisin' for a Cure**  
Iowa Chapter  
\$16,598

**Minneapolis Team Hope Walk**  
Minnesota Chapter  
\$15,937



## GREAT LAKES REGION

(Wisconsin, Michigan, Illinois, Indiana, Ohio, Missouri, Kentucky)

**Naperville Team Hope Walk**  
Illinois Chapter  
\$115,450

**Chicago Celebration of Hope**  
Great Lakes Region  
\$72,672

**Liberty Team Hope Walk**  
Great Lakes Region  
\$38,000



## NEW YORK / NEW JERSEY REGION

(New York, New Jersey)

**NYC Team Hope Walk**  
NYC Chapter  
\$104,600

**New Jersey Team Hope Walk**  
NJ Chapter  
\$39,122

**Fishy Frolic**  
Albany Chapter  
\$24,891



## NEW ENGLAND REGION

(Vermont, New Hampshire, Maine, Massachusetts, Rhode Island, Connecticut)

**Celebration of Hope — James Bond Style**  
New England Region  
\$61,212

**Tewksbury Team Hope Walk**  
MA/RI Chapter  
\$44,747

**Maine Team Hope Walk**  
Maine Affiliate  
\$25,779



## MID-ATLANTIC REGION

(District of Columbia, Delaware, Maryland, Virginia, West Virginia, Pennsylvania)

**Woods Warrior**  
Western PA Chapter  
\$10,377

**Fast Track**  
Western PA Chapter  
\$7,163

**Erie Team Hope Walk**  
Mid-Atlantic Region  
\$4,839



Huntington's Disease  
Society of America

# CONVENTION

## Virtual 35<sup>th</sup> Annual HDSA Convention

**Due to the COVID-19 pandemic, the Huntington's Disease Society of America transitioned the 35<sup>th</sup> 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 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 **Virtual Convention**, and the HD Community came out in full force. **More than 1,500 unique email registrants** joined the Convention, and on average, there were **345 viewers per session**. Impressively, participants from **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 80<sup>th</sup> 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 Moser**.

On Saturday, HDSA's Chief Scientific and Mission Officer, **Dr. George Yohrling** hosted the **Research Forum** which included updates from **Annexon Biosciences, Wave Life Sciences, Roche/Genentech, 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 36<sup>th</sup> Annual HDSA Convention location in 2021**.

The culminating event was the presentation of **HDSA's National Awards** to **HDSA South Carolina Affiliate (Affiliate of the Year), Autumn Furnisen (Youth/JHD 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 **Candle Lighting 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 Virtual 35<sup>th</sup> Annual HDSA Convention! We look forward to seeing you in Spokane, Washington next year on June 10-12, 2021!**

**Thank you to our generous sponsors that made the 35<sup>th</sup> Annual HDSA Convention possible!**

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To view all recorded Convention sessions, please visit [HDSA.org/convention](https://HDSA.org/convention)



## May: Huntington's Disease Awareness Month

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 15<sup>th</sup>**, 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](https://HDSA.org/youtube).*

## 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.



Anne Leserman

## Here's The Deal

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](https://HDSA.org/heresthedeal)**

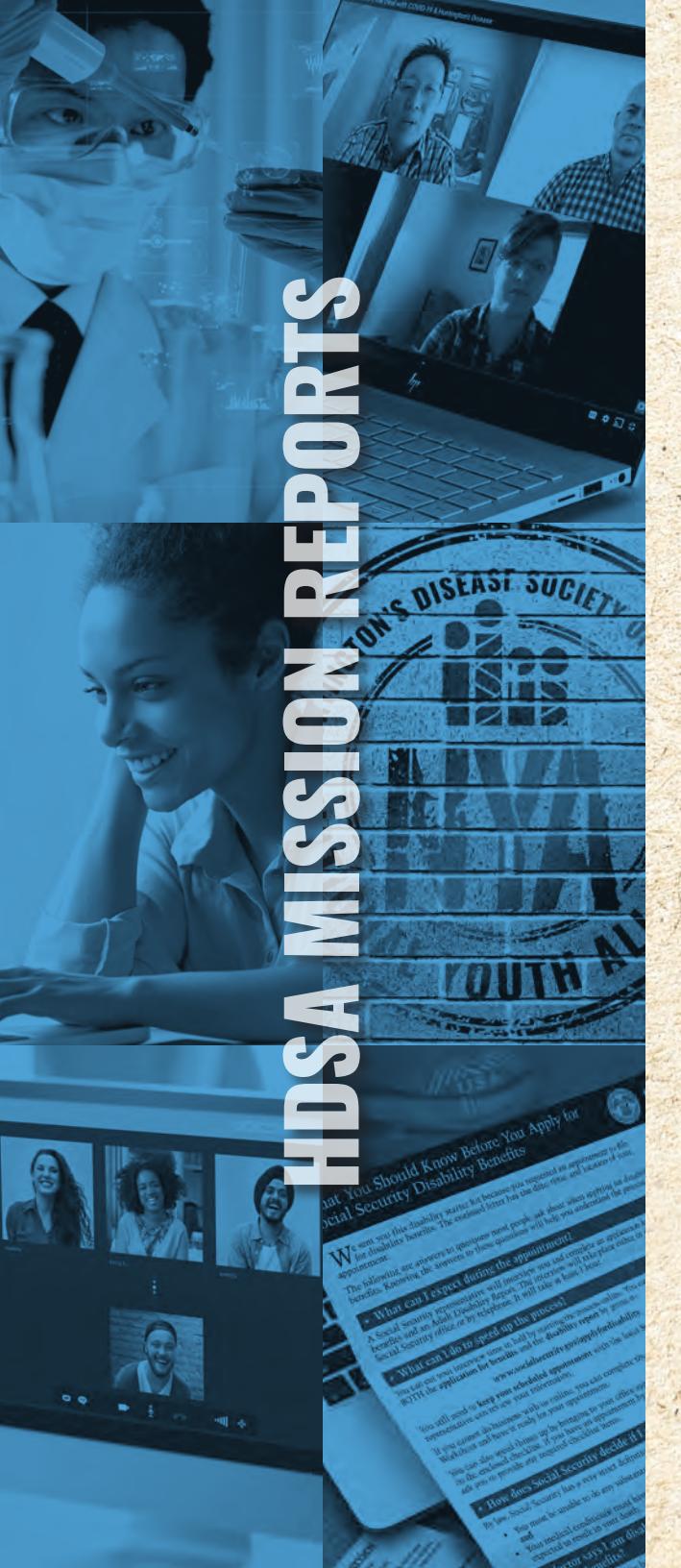
Jennifer Simpson (at left) with guest, HDSA National Youth Alliance Board member Gia Mannone, on HDSA's web series, Here's the Deal.



## HDSA & Me Webinar Series Educate. Engage. Empower.

**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/hdsa-me](https://HDSA.org/hdsa-me)**



## RESEARCH

BY GEORGE YOHLING, Ph.D.

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**



## ADVOCACY

BY JENNIFER SIMPSON, LCSW

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 unprecedented 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 Precision-HD1/2**, 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!

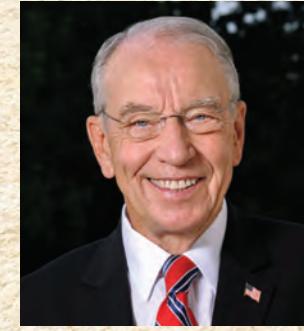


GEORGE YOHLING, Ph.D. is HDSA's Chief Scientific Officer and Chief Mission Officer  
[gyohrling@HDSA.org](mailto:gyohrling@HDSA.org)

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 HDSA'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, among other important HD topics.

We also pushed for the **HD Parity Act** during the pandemic, setting up virtual meetings with community members and their Senators, including



Senator Chuck Grassley (R-IA)



Senator Tim Scott (R-SC)



Senator Todd Young (R-IN)

HD Parity Act is,

how crucial immediate care is for our community, and how important 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](https://HDSA.org/takeaction)**



JENNIFER SIMPSON, LCSW is HDSA's Assistant Director of Youth & Community Services  
[jsimpson@HDSA.org](mailto:jsimpson@HDSA.org)



HDSA set up virtual meetings with Senators Chuck Grassley, Tim Scott and Todd Young to discuss the importance of passing the HD Parity Act.

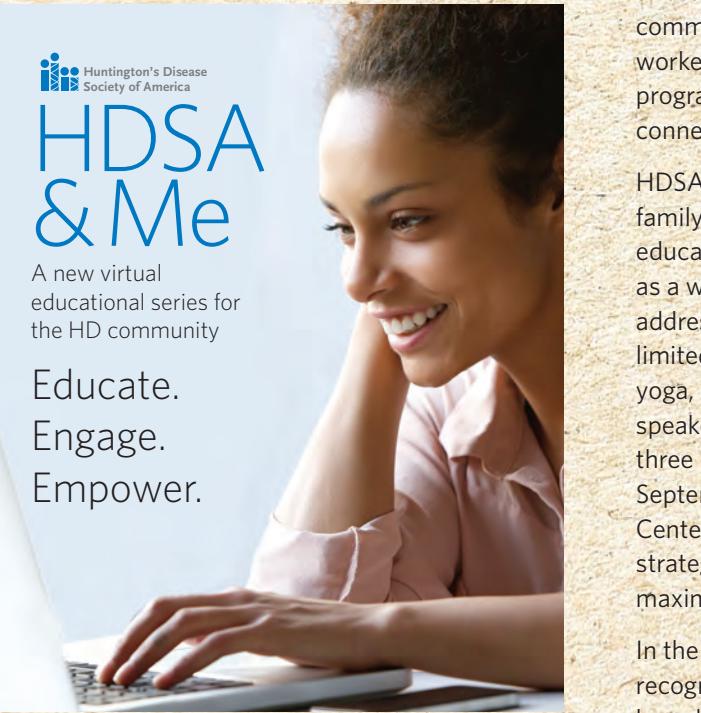
(AT RIGHT) Dr. Victor Sung and Dr. Arik Johnson join Jennifer Simpson to discuss COVID-19's impact on the HD community on an episode of *Here's the Deal* in April.

# EDUCATION

BY DEBRA LOVECKY, MS

Hindsight is 2020 and thus when we look back on this extraordinary year through the lens of time, it will be as important to remember all that we accomplished in the midst of unprecedented times as it is to lament the losses we experienced.

While the largest educational event HDSA holds each year, the **HDSA Convention**, evolved into a virtual educational and family gathering, it in no way paled to any preceding in-person Convention.



To view HDSA & Me visit [HDSA.org/hdsa-me](#)

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 end the year, **HDSA will have presented diverse educational programming through seven in-person, pre-pandemic events and 29 virtual education events for a total of 36 unique offerings**. Compared with 2019, when HDSA hosted 59 educational days, this is a true testament to the dedication and commitment of our volunteers and leadership who worked very hard to provide not only compelling programming for our families but also a sense of connection during these challenging times.

HDSA also launched **HDSA & Me**, a new hour-long 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 yoga, dance, exercise, music and inspirational speakers to HD families across the country. After a three month summer hiatus, **HDSA & Me** returned in September with a roster of speakers from our HDSA Center of Excellence program that focused on strategies for caregivers and persons with HD to maximize the increased use of telehealth services.

In the area of professional education, HDSA recognized the increased need for more HD knowledgeable genetic counselors as disease modifying therapies near approval.

**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 more about the unique issues surrounding both presymptomatic and symptomatic genetic testing for Huntington's disease while earning free CE units. From April through the end of November the course attracted more than 900 users 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 435 CE hours to occupational therapists.

Even as 2020 challenged the way that HDSA offered education to our families and our health-care 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.

**DEBRA LOVECKY, MS** is HDSA's Director of Educational Programs.  
[dlovecky@HDSA.org](mailto:dlovecky@HDSA.org)

# YOUTH PROGRAMS

BY JENNIFER SIMPSON, LCSW

After seeing the success 2019's **Youth Social Worker Pilot Program**, two more social workers joined the team in order to better provide additional resources for youth in the community in 2020. In the midst of planning 2020 events for **HDSA's National Youth Alliance (NYA)** members, the COVID pandemic hit the world — bringing challenges and experiences, none of us could have planned for. The pandemic turned all in-person events into virtual online experiences, that found new, inventive ways to provide young people support, resources, a sense of belonging, and a place for them to meet others affected by HD/JHD.

Despite not being able to see one another in person, we were able to reach more people during **HDSA's Virtual Convention**, with record numbers of people logging in to see, learn, and find support.

As we saw our youth needing more content, and less screen time, we created **NYA Virtual Miniseries** focusing on different important topics every other Saturday for 1-2 hours led by our youth social workers and NYA board members. As they continue to be successful, we will continue to develop more topics and ways to keep young people connected and provide online resources until we are able to safely host our **NYA Youth Retreats** again.

The challenges of 2020 did not stop our NYA members from spreading awareness, and sharing their stories on all different platforms whenever they could. There is no stopping this community and we will continue to grow stronger, together.

Although great things have happened virtually, we hope and can't wait to see everyone in person again! 2021 will be filled with more amazing experiences,

support, connections, and resources for our young people in the community.

**Learn more at [HDSA.org/NYA](#)**



**JENNIFER SIMPSON, LCSW** is HDSA's Assistant Director of Youth & Community Services  
[jsimpson@HDSA.org](mailto:jsimpson@HDSA.org)



In 2020, the NYA received a makeover with a new logo as this inspiring group continued their mission to improve the lives of young people affected by HD and their families.

# SUPPORT & SERVICES

BY JENNIFER SIMPSON, LCSW

2020 saw a giant leave our community. **Anne Leserman**, our Assistant Director of Community Services, retired after many years of dedicated service to the HD Community. (See story on page 17). Although we were heartbroken to see Anne leave us, we wish her well in her retirement and many years of happiness with her husband, children and dog Gracie.



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

**Jennifer Simpson** stepped into the role of Assistant Director of Youth & Community Services, and brought on **MaryAnn Emerick** as the Manager of Youth & Community Services to assist in the management of the youth, advocacy and social work programs.

HDSA maintained a roster of 25 chapter and

regional social workers, with the onboarding of social workers into new positions including Eastern Washington state and other areas where chapters and affiliates had worked hard to make these 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 of **national online support groups**. We expanded our online support group offerings to include groups for young adults, family planning and beginning your HD journey.

HDSA also began a process of reviewing our nation-wide 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 networks 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 in 2021.

*Learn more at [HDSA.org/support](https://HDSA.org/support)*



**JENNIFER SIMPSON, LCSW** is HDSA's Assistant Director of Youth & Community Services  
[jsimpson@HDSA.org](mailto:jsimpson@HDSA.org)

# DISABILITY PROGRAMS

BY ALLISON BARTLETT, ESQ.

## Ask Allison!

Families and many 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. For weekly disability updates, check out the **Disability Tip of the Week** on Facebook, Instagram, or Twitter, that was started in February 2020.

The **Disability Chat Webinar Series** is still going strong and webinars are hosted every other month, this year's topics included starting the disability process, disability myths, completing disability forms, and the legal and disability considerations for prodromal and early to mid-stage HD. To date, Disability Chat has had 422 live views and 1,400 recorded views. Several new resources were created

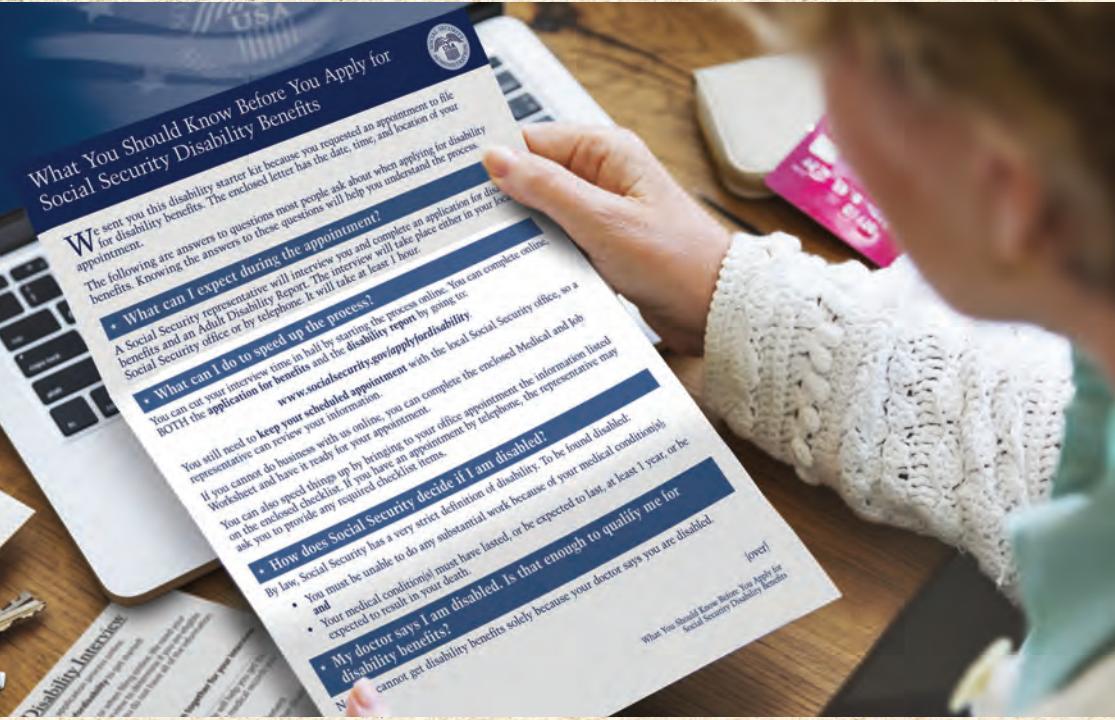
for families and social workers this year to help with the Social Security disability application process including a **Social Worker Disability Starter Kit**, Social Security process infographic, disability onset date worksheet, question guide to help determine HD symptoms and limitations, HD medical source statement, disability and legal resource preparation checklists, and a disability appeal guide for completing the online Social Security disability appeal.

**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](mailto:abartlett@HDSA.org).**

*Learn more at [HDSA.org/disability](https://HDSA.org/disability).*



**ALLISON BARTLETT, ESQ** is HDSA's Manager of Disability Programs.  
[abartlett@HDSA.org](mailto:abartlett@HDSA.org)



To assist with the disability application process, a Social Worker Disability Starter Kit has been developed.



# Save the Dates!



**PLEASE NOTE:** Our ability to host the 36<sup>th</sup> Annual HDSA Convention in Spokane is dependent on federal, state and local public health guidelines. Please check [www.HDSA.org](http://www.HDSA.org) regularly for updated information. Thank You!



Huntington's Disease  
Society of America

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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](http://HDSA.org/osg)
- **Telehealth:** [HDSA.org/telehealth](http://HDSA.org/telehealth)
- **Disability Services:** [HDSA.org/disability](http://HDSA.org/disability)
- **Clinical Trial Participation:** [HDtrialfinder.org](http://HDtrialfinder.org)
- **Locate Resources Near You:** [HDSA.org/locateresources](http://HDSA.org/locateresources)

## HIGHEST RATINGS

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

