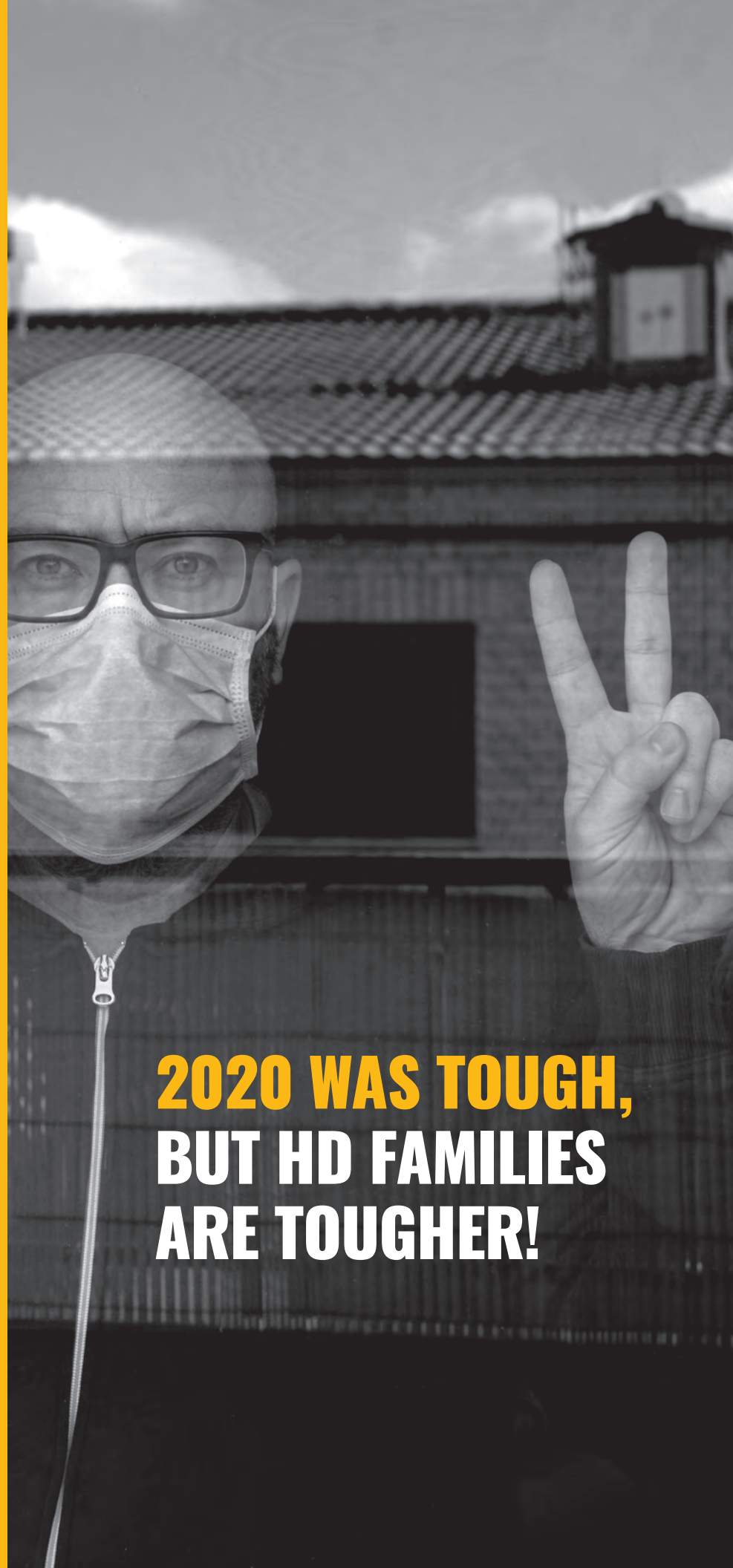




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**2020 WAS TOUGH,  
BUT HD FAMILIES  
ARE TOUGHER!**

## Dear Friends of HDSA,

2020 was a year filled with challenges, but it has definitely 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.

Thanks to the inspiring generosity of our donors, HDSA did not cut any of the vital support services that HD families need, especially during the pandemic.

As we look for the silver lining in the challenges we have faced, HDSA has become experts in virtual events and online support resources. Our telehealth program and online support groups helped record numbers of families, while our comprehensive website [www.HDSA.org](http://www.HDSA.org) recorded more visits than ever before.

Despite the challenges, we never wavered in our pledge providing more resources to HD families around the United States and funding vital HD research. 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.

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

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. Events like the virtual 6<sup>th</sup> Annual Freeze HD event, generated the exceptional resources and visibility that keeps HDSA's mission work strong, even during the hardest times.

Thank you for your continued support in the fight against Huntington's disease.

Sincerely,

**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 were 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. **HDSA awarded 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://www.hdsa.org/COE).*

### HDSA MILESTONE

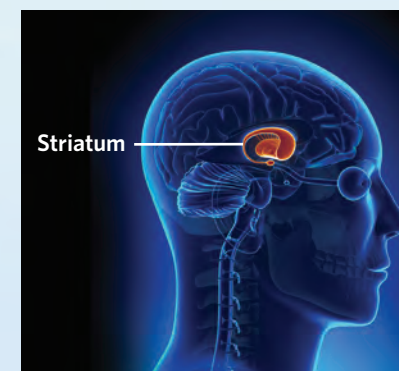


### CENTERS NATIONWIDE



## 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 **uniQure 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.



Dr. Yasaman Gholamalipour

"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."

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

- 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*

**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.

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



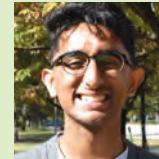
Sophia completed her project at the Massachusetts Institute of Technology with **David Housman, PhD**, exploring genes known to alter the onset of Huntington’s disease symptoms.

**Amber Keith**  
University of California at Irvine



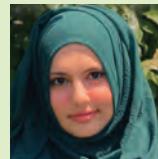
Amber worked under the guidance of **Sarah Hernandez, PhD**, a 2017 HDSA Berman-Topper Career Development Fellowship recipient, in the laboratory of **Dr. Leslie Thompson**, to develop a model of the blood-brain barrier derived from human cells.

**Lav Patel**  
Ohio State University



Lav spent 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 worked 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 was mentored by former HDSA Human Biology Fellow **Dr. Amber Southwell** and will study aggression in mouse models of Huntington’s disease.



**HDSA Awards Four 2020 HD Human Biology Project Fellowships**

In December, the Huntington’s Disease Society of America announced that four research grants were 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.

Below 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 Laganieri, 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



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

## ABC News Story on Huntington's Disease

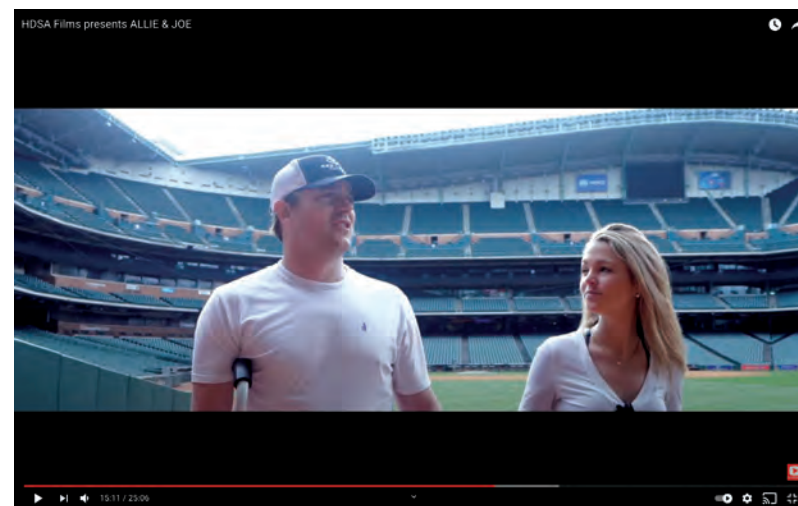
On July 3<sup>rd</sup>, **ABC News collaborated with HDSA to produce a powerful story on Huntington's disease.** The 16-minute segment featured ABC News' anchor **Linsey Davis** following two families grappling with the rare genetic disorder.

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

## 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)



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 Series



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.

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](https://www.hdsa.org/coffeewalk)



## 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!



## 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 \$1,500 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](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.**



## 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.**

This Land Is Your Land!



Ito Smith



Marc Scibilia performs Woody Guthrie's classic This Land Is Your Land.

## 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, Gentile 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)**



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.

### Thank You to Our Generous Sponsors!

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### One Dime at a Time!

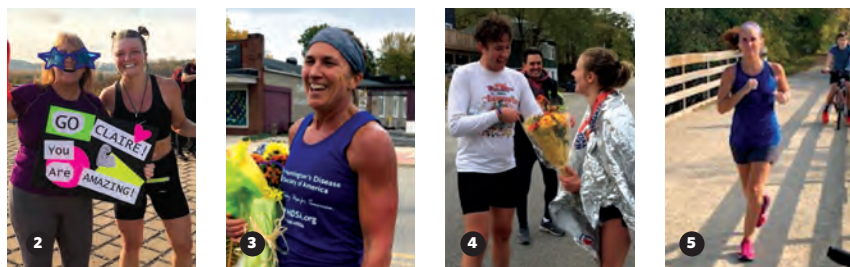
Michigan-native **Ashley Greenway** reached her goal of **\$10,000** by collecting soda cans throughout her community. In Michigan, each returned can is worth ten cents. She collected cans throughout the year from her entire town. She would do pick-ups from neighbors and friends almost every day. Quick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

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.



### 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](https://www.hdsa.org/blog)



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

### #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



Yousef Gamal El-Din

### 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

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](https://www.hdsa.org/NYA).*



### HDSA Social Media

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

- Facebook: [facebook.com/HDSofA](https://www.facebook.com/HDSofA)
- Twitter: [twitter.com/HDSA](https://twitter.com/HDSA)
- Instagram: [instagram.com/HDSAnational/](https://www.instagram.com/HDSAnational/)
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- LinkedIn: [linkedin.com/company/huntington-s-disease-society-of-america/](https://www.linkedin.com/company/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 and 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."

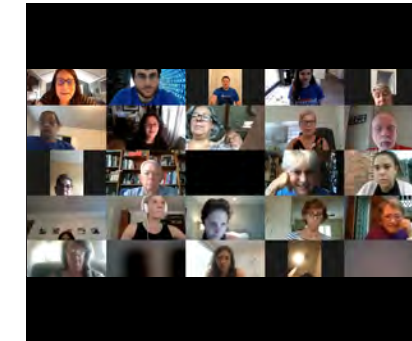
The Virtual Convention featured nearly all of the regularly scheduled Convention programming with some surprise special guests. The **Welcome Reception** on Thursday included a virtual concert featuring performances by **Marc Scibilia, The Mammals and Dave Hause**. Marc Scibilia paid tribute to the 80<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 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!**

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

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

|  |   |  |
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**VIRTUAL 35<sup>th</sup> annual HDSA convention**  
june 4-7, 2020

**VIRTUAL HDSA CONVENTION BY THE NUMBERS**

- 4 days of online presentations
- 40+ sessions
- 93 nations represented
- 365+ viewers per session on average
- 645 viewed the HDBuzz presentation — the Convention's most attended session
- 942 Convention app downloads
- 1,536 unique email registrants
- 3,211+ unique visitors to the Virtual Exhibit Hall
- 6,200 live views



# HD AWARENESS



## 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://www.hdsa.org/youtube).*

# FINANCIALS

## Your HDSA Dollars at Work

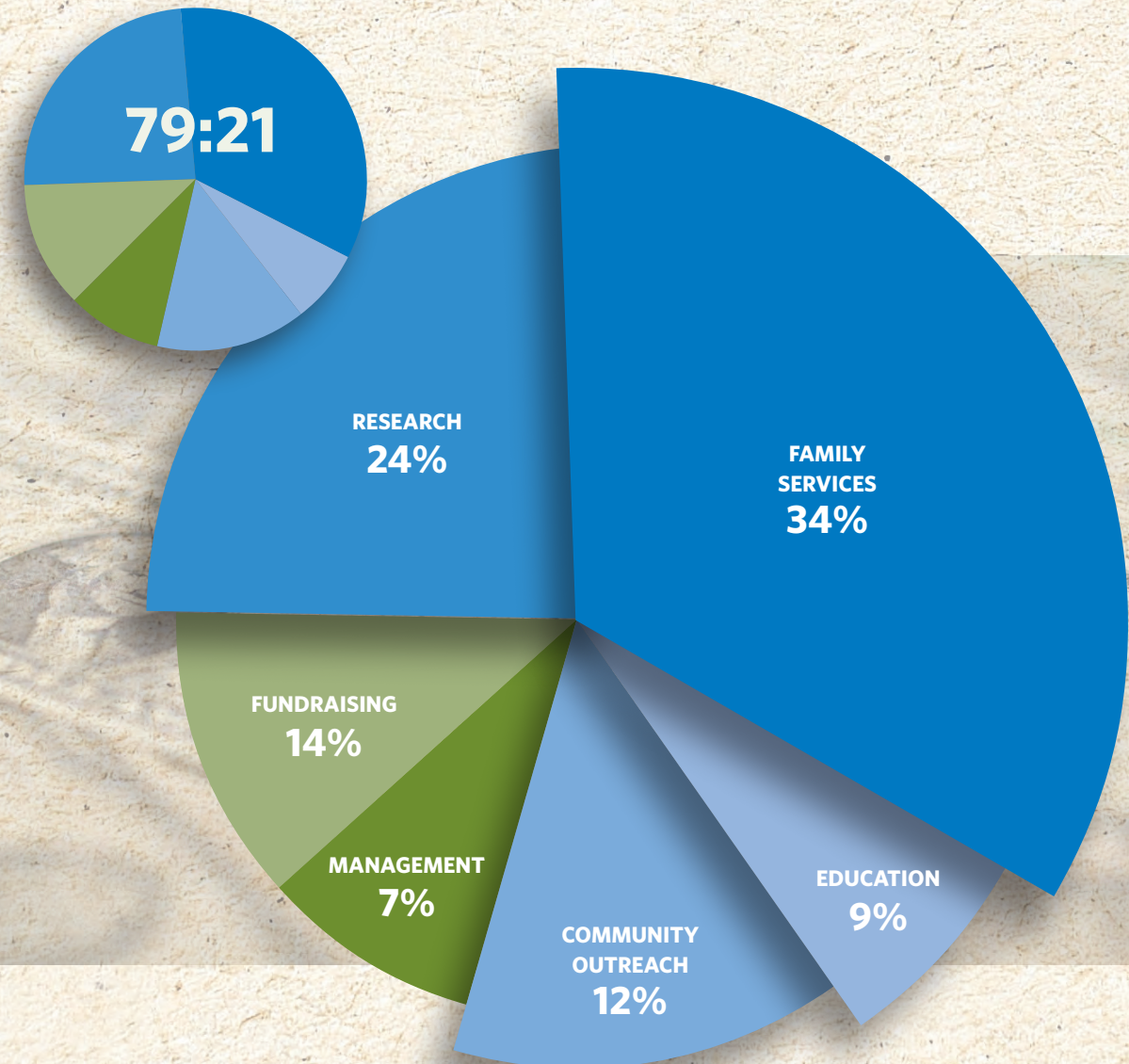
BASED ON AUDITED FINANCIALS FOR FISCAL YEAR ENDED DECEMBER 31, 2020

### MISSION RATIO AND FUNDS ALLOCATION

- Program Services: 79%
- Administration: 21%

### OVERVIEW

- Total 2020 revenue of \$8.97 million.
- Funded \$2.61 million in new grants.  
*HDSA Centers of Excellence and research grants.*



## Statements of Financial Position

AS OF DECEMBER 31, 2020 AND 2019

|   | 2020              | 2019              |
|---|-------------------|-------------------|
| <b>ASSETS</b>                             |                   |                   |
| Cash and cash equivalents                 | \$ 9,339,030      | \$ 8,337,091      |
| Pledges and contributions receivable, net | 1,133,748         | 1,221,960         |
| Investments                               | 2,310,097         | 2,069,844         |
| Prepaid expenses and deposits             | 154,406           | 167,544           |
| Property and equipment, net               | 35,148            | 55,849            |
| Website costs, net                        | 39,529            | 61,469            |
| <b>Total Assets</b>                       | <b>13,011,958</b> | <b>11,913,757</b> |
| <b>LIABILITIES</b>                        |                   |                   |
| Accounts payable and accrued expenses     | 214,836           | 101,723           |
| Accrued compensation                      | 294,228           | 265,315           |
| Grants payable, net                       | 1,283,055         | 1,088,162         |
| Event revenue received in advance         | 17,800            | 71,174            |
| Paycheck Protection Program loan payable  | 634,692           | —                 |
| Deferred rent obligation                  | 114,721           | 118,993           |
| Obligation under capital lease            | 3,734             | 8,536             |
| <b>Total Liabilities</b>                  | <b>2,563,066</b>  | <b>1,653,903</b>  |
| <b>NET ASSETS</b>                         |                   |                   |
| <b>Without donor restrictions</b>         |                   |                   |
| Undesignated                              | 4,114,838         | 2,838,422         |
| Board-operating reserve                   | 1,805,969         | 1,796,131         |
|   | 5,920,807         | 4,634,553         |
| <b>With donor restrictions</b>            |                   |                   |
| Purpose restrictions                      | 4,178,135         | 5,144,869         |
| Time-restricted for future periods        | 99,950            | 230,432           |
| Perpetual in nature                       | 250,000           | 250,000           |
|   | 4,528,085         | 5,625,301         |
| <b>Total Net Assets</b>                   | <b>10,448,892</b> | <b>10,259,854</b> |
| <b>Total Liabilities And Net Assets</b>   | <b>13,011,958</b> | <b>11,913,757</b> |

**NOTE:** These Consolidated Statements reflect HDSA's operations for the fiscal years as stated and include all affiliates. Please contact the HDSA National Office for a full copy of the audited financial statements.

## Consolidated Statements of Activities

YEAR ENDED DECEMBER 31, 2020 WITH SUMMARIZED FINANCIAL INFORMATION FOR 2019

|  | 2020              | 2019              |
|--|-------------------|-------------------|
| <b>SUPPORT &amp; REVENUE</b>   |                   |                   |
| Public donations   | 3,116,252         | 4,209,337         |
| Foundation grants and corporate contributions  | 3,115,452         | 2,568,769         |
| Federated campaign   | 246,913           | 271,027           |
| Special events (net of direct benefit to donors of \$212,622 and \$618,196 in 2020 and 2019, respectively) | 2,254,487         | 4,158,871         |
| Investment (losses) earnings, net  | 21,904            | 26,227            |
| Donated services and materials   | 132,439           | 404,183           |
| Other income   | 83,178            | 162,359           |
| Total support and revenue before net assets released from restrictions                                     | 8,970,625         | 11,800,773        |
| Net assets released from restrictions  | 0                 | 0                 |
| <b>Total Support and Revenue</b>   | <b>8,970,625</b>  | <b>11,800,773</b> |
| <b>EXPENSES</b>  |                   |                   |
| <b>Program services:</b>   |                   |                   |
| Research   | 2,102,371         | 1,753,479         |
| Family services  | 3,083,605         | 2,976,990         |
| Education  | 761,119           | 1,833,920         |
| Community outreach   | 1,023,900         | 1,177,664         |
|  | 6,970,995         | 7,742,053         |
| <b>Supporting services:</b>  |                   |                   |
| Management and general   | 592,598           | 578,718           |
| Fundraising  | 1,217,994         | 1,837,073         |
|  | 1,810,592         | 2,415,791         |
| <b>Total Expenses</b>  | <b>8,781,587</b>  | <b>10,157,844</b> |
| Change in net assets   | 189,038           | 1,642,929         |
| Net assets - beginning of year   | 10,259,854        | 8,616,925         |
| <b>Net Assets - End of Year</b>  | <b>10,448,892</b> | <b>10,259,854</b> |

**NOTE:** These Consolidated Statements reflect HDSA's operations for the fiscal years as stated and include all affiliates. Please contact the HDSA National Office for a full copy of the audited financial statements.

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Gentex Corporation  
Georgetown Healthcare System  
Get-R-Down Tree Service  
Givegab.Com  
Givinga Foundation  
Global Charitable Fund

Global Gateway Advisors  
 Global Prairie  
 Goodman Real Estate Services Group, LLC  
 Greater Horizons  
 Greater Kansas City Community Foundation  
 Grestle, Rosen & Goldenberg, P.A.  
 Grey Search & Strategy  
 Hampshire Community United Way  
 The Happy Crafter  
 Hardinwaldrip Law  
 Heart of the House  
 Hospicom  
 Huntington Study Group  
 Hy-Vee, Inc.  
 ING Financial Services, LLC  
 Inland Northwest Research Foundation  
 Innovative Analytics  
 Insurance Professionals of Orange County  
 Jack & Penny Rohrbach Family Foundation, Inc.  
 Joe Hillman Plumbers  
 Joseph M. Hurwitz Living Trust  
 JP Morgan Chase Foundation  
 JP Morgan Chase Workplace Giving  
 JVD., Inc. dba Degrandis & Degrandis  
 Kaiser Foundation Health Plan of the  
 Northwest Community Giving Campaign  
 Kansas City Series of Lockton Companies, LLC  
 Kelley Kronenberg, P.A.  
 Kendra Scott, LLC  
 Keyes Real Estate  
 KPMG Gives  
 c/o Bergen County's United Way  
 Krahenbill CPA Tax Services, LLC  
 Kroger  
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 Libshap Realty Corporation  
 Linda Law Clark  
 Lions Club of Webster Groves  
 Lockton Cares, Inc.  
 Lofty Asset Management, Inc.  
 Los Alamos National Laboratory  
 LPL Financial  
 LXI Components, Inc.

Mack Cycle & Fitness  
 Make My Donation, Inc.  
 Marron Foods  
 Medtronic Foundation  
 Meyers, Roman, Friedberg & Lewis  
 Michael L. Runyan Memorial Tournament  
 Michael Skurnik Wines, Inc.  
 Money Max Mortgage, Inc.  
 Monsieur Touton Selection  
 The Moritz Jenkins Charitable Fund  
 MSC Filtration Technologies, Inc.  
 Nebraska Medical Center  
 Netflix  
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 Neuroscience Associates  
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 Nexxis Solutions, Inc.  
 Northwestern University  
 The Nurture Foundation  
 Oak Harbor Freight Lines, Inc.  
 Origami Therapeutics, Inc.  
 Pfizer, Inc.  
 PhRMA  
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 Praxis Engineering Technologies, Inc.  
 Precision Bioservices, Inc.  
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 Prestige Employee Administration, Inc.  
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# Special Thanks

*We are grateful for the gifts  
 from the following estates who  
 helped make our work possible  
 in 2020.*



Barbara L. Bell Trust  
 Estate of Charlotte F. Calhoun  
 Estate of Lenore Feldman  
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 Estate of Marc Clay Shurtleff  
 United Life Insurance Company

# PLANNED GIVING

## The Marjorie Guthrie Society

Until the day when scientists find a cure for HD, families across the country require access to the crucial research, care, education, and advocacy programs HDSA provides. **The Marjorie Guthrie Society** ensures that as we look to the future we'll have the resources we need to continue providing help and hope to the HD community.

By including HDSA in your estate plans as the beneficiary of insurance, real estate, appreciated securities, or retirement plan you can create a legacy of giving that guarantees future generations will have the vital support they need to confront this devastating illness. With the help of a financial planner, you can arrange your gift in a way

that reduces your estate taxes and has the strongest possible impact on the lives of those affected by HD in the decades to come.

*To learn more about the Marjorie Guthrie Society, or to inform us of your estate plans to support HDSA, please contact Jamison Skala, Director of National Development, at (212) 242-1968 ext. 235 or [jskala@hdsa.org](mailto:jskala@hdsa.org).*



Woody and Marjorie Guthrie

Join us in thanking the following individuals who have committed to support HDSA through their estate plans:

Anonymous (3)

Norman Baldwin

Jerzy Gajewski

Catherine Hayes & Mark Wiesel

Dr. Barbara Heere

Daniel & Katy Leonard

Mark Pinto

Gordon Sparks

Craig & Teresa Srajer

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## HUNTINGTON'S DISEASE SOCIETY OF AMERICA

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



## 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:



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