

2021 Annual Report



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President & CEO's Message

Dear Friends of HDSA,

After navigating through another year of COVID-19 and moving more events to virtual platforms, HDSA continued push forward to improve the lives of families impacted by Huntington's disease. On top of all the challenges of a pandemic, we received disappointing research news earlier in the year. With all the challenges we faced, the HD Community remained relentless in our fight against HD and we cannot thank our donors and loyal corporate partners enough for their amazing support.

In early 2021, we expanded HDSA's Centers of Excellence program to a record 54 HD care teams with eight satellite sites across the country. We funded five research grants under the Society's largest research initiative, the HDSA Huntington's Disease Human Biology Project. We also awarded two Berman-Topper Family HD Career Development Fellowships, and two Donald A. King Summer Research Fellowships, a vital program to train the next generation of scientists with research expertise in Huntington's disease. For a full breakdown of HD research from this past year, I encourage you to read *The Marker:* HDSA's 2021 Research Report which can be found at HDSA.org/marker21.

For the second consecutive year, the **Annual HDSA Convention** was moved to a virtual event where we welcomed thousands from across the globe. Thanks to the commitment of our speakers, exhibitors and sponsors, as well as the dedicated volunteers who once again ensured that the extraordinary magic of HDSA Conventions was preserved.

Our extraordinary volunteers stepped up in the face of adversity to coordinate creative events that allowed folks to participate in HDSA's mission work in many ways. A prime example is the virtual **Seventh Annual Freeze HD event** held

in October that raised more than \$212,000 and generated an enormous amount of awareness thanks to the amazing work of the Freeze HD Committee.

Aside from the events and fundraising initiatives, the power of storytelling helped HDSA generate more than **two billion** media impressions — the most ever! During a very 'loud' media year filled with political and health headlines, this meant that HDSA news and Huntington's disease stories reached more people than ever before to educate and motivate them in our work. The fight to continue to raise much-needed awareness continues to be an integral part in educating the world about HD.

One such major news story occurred in July when **Kala Booth** testified in front of Congress to encourage the passage of the **HD Parity Act.** With our most comprehensive push yet to move this crucial bill forward, HDSA volunteers from across the country have come together to contact their local representatives and build momentum for this important bill. From educational and fundraising events to advocacy and awareness, HDSA is able to provide help for today, hope for tomorrow for families affected by HD because of you. Your relentless commitment is ensuring help and hope, until we finally live in a world free of HD. Thank you for your continued support!

With hope,

Quin Vetr

Louise VetterPresident & Chief Executive Officer

HDSA Centers of Excellence

HDSA Expands Centers of Excellence Network to 54 Clinics and Adds Eight Partner Sites

In February, HDSA announced that fifty-four outstanding
Huntington's disease care facilities were
awarded the designation of HDSA Centers
of Excellence. In 2021, HDSA awarded
\$1,750,000 to the Centers of
Excellence network.

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 HDSA Centers of Excellence network allows expanded access to expert HD clinical care and clinical trial opportunities to more families across the United States. With new Centers in Arizona, Arkansas, New Jersey, Mississispipi, Ohio and South Carolina, HDSA

now offers care locations in 35 States plus the District of Columbia.

"The expansion of the HDSA Centers of Excellence program ensures that more families affected by

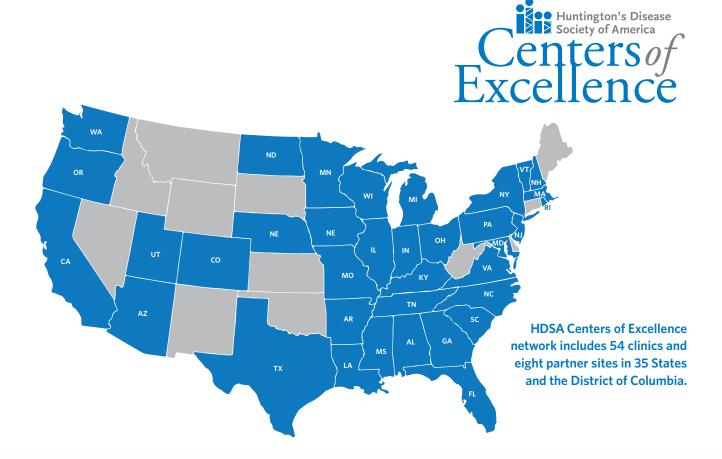
Huntington's disease have increased access to expert and comprehensive care for this devastating rare brain disease," said **Dr. Victor Sung, Chair** of HDSA's National Board of Trustees and Director of the HDSA Center of Excellence at The University of Alabama, Birmingham.

"Additionally, clinical research conducted

at many HDSA Centers of Excellence is vital to the development of potentially life-changing treatments to improve the lives of everyone affected by Huntington's disease."

Learn more about HDSA's Centers of Excellence network, by visiting HDSA.org/coe.





HDSA Centers of Excellence Clinical Research Pilot Program

HDSA awarded two grants under the HDSA Centers of Excellence Clinical Research Pilot Program. These grants, totaling \$25,000, represent HDSA's patient-centric research focus by fostering novel clinical research projects within the HDSA Centers of Excellence network. These pilot projects will unite scientists with HD families through their direct participation in clinical research. Two clinical research pilot grants were awarded this year.

Deb Kegelmeyer,
DPT, at The Ohio
State University.
This study will
evaluate whether
telehealth is an
effective medium to implement
a 12-week movement to music
program designed to enhance
physical, cognitive, and psychosocial
health in adults, as well as whether
the intervention leads to changes

in these domains.

Leonard Sokol, MD, at Northwestern
University, for a study on Meaning-Centered Psychotherapy for treatment of psychosocial symptoms and improved quality of life in persons with Huntington's disease.



HDSA Research Grants

2021 Human Biology Project Fellowships

In October of 2021, HDSA awarded five research grants under the Society's largest research initiative, the HDSA Huntington's **Disease Human Biology Project.** Totaling more than \$728,000, 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 animal models, with direct participation of people affected by HD. HDSA received impressive applications from researchers all around the world. After careful consideration by HDSA's Scientific Advisory Board, funds were ultimately granted to researchers from the United States, Canada, and Spain.



Ana Gámez-Valero, PhD Postdoctoral Research Scientist University of Barcelona

Plasma extracellular small RNAs as early biomarkers of HD and indicators of dynamic changes in disease progression



Tamara Maiuri, PhD Research Associate McMaster University

Poly ADP-ribose dysregulation in HD patient samples and potential for therapeutic intervention



Joan O'Keefe, PhD, PT **Associate Professor Rush University**

Neural underpinnings of cognitive, balance, and gait deficits in HD



Alby Richard, MD, PhD **Assistant Professor and Neurologist University of Montreal**

Oculomotor learning as a biomarker in Huntington's disease patients



Charlene Smith-Geater, PhD Assistant Project Scientist University of California, Irvine

Modulation of E3 SUMO- ligase PIAS1 in 3D cortico-striatal assembloids and investigation of the HD- relevant CSF SUMO-ome

2021 Donald A. King Summer Research Fellowships

With the goal of attracting the next generation of bright young scientists to HD research and preparing them for the challenges of the field, HDSA established the **Donald A. King Summer Research Fellowship** in 2005 to support undergraduate researchers in their study of biological mechanisms underlying HD pathology. This program was established to honor **Donald A. King,** a tireless advocate for HD families who served as HDSA's Chairman of the Board from 1999 to 2003 before his sudden passing in 2004.





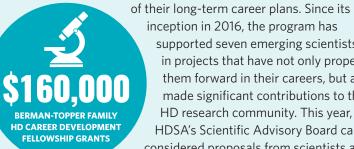
Russell Wells Whitworth College Mentor: Michael Sardinia, PhD, DVM



2021 Berman-Topper Family HD Career Development Fellowships

With a shared goal of bolstering opportunities for young HD researchers and generous support from the **Berman** and Topper families, HDSA launched the **Berman-Topper HD Career Development Fellowship** in 2016 to support future genera-

tions of passionate HD scientists and clinicians. These prestigious fellowships provide \$80,000 of annual funding for three years to young scientists and clinicians who are motivated to make HD a focal point



inception in 2016, the program has supported seven emerging scientists in projects that have not only propelled them forward in their careers, but also made significant contributions to the HD research community. This year, after HDSA's Scientific Advisory Board carefully considered proposals from scientists across the globe, the Society was excited to name

two 2021 Berman-Topper Fellows, Dr. Eduardo Silva-Ramos and Dr. Advs Mendizabal.



Dr. Adys Mendizabal

University of California, Los Angeles Mentor: Dr. Yvette Bordelon

HD epidemiology, healthcare utilization, and outcomes in racially and ethnically diverse populations in the US



Dr. Eduardo Silva-Ramos

Max Delbrück Center for Molecular Medicine Mentor: Dr. Erich Wanker

Characterization and targeting a novel HTT interacting E3 ligase protein complex



2021 HDSA Highlights

Dr. Jeff Carroll & Dr. Beth Hoffman **Join HDSA's National Board of Trustees**

"On behalf of HDSA's Board of Trustees, we are excited to welcome Dr. Carroll and Dr. Hoffman" said HDSA's President and CEO Louise Vetter. "They are both established scientific and volunteer leaders in the HD community whose experience will undoubtedly strengthen HDSA's mission work."

For more information about HDSA's National Board of Trustees, please visit www.HDSA.org/bot



Jeff Carroll, PhD



Beth Hoffman, PhD

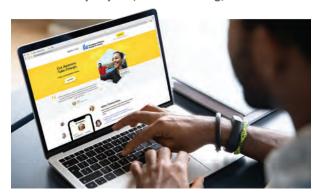
HDSA Partners With PatientsLikeMe®

The world's largest integrated community, health management, and real-world data platform PatientsLikeMe (PLM) announced in June 2021 that it partnered with the Huntington's Disease Society of America to launch a virtual community for those living with Huntington's disease and for those caring for individuals living with HD. This tailored community will focus on education and peer-to-peer knowledgesharing. This community will serve as a catalyst to expand researchers' knowledge of the condition through the analysis of patient-generated data.

"Partnering with PatientsLikeMe is an exciting new step in our work to help families affected by Huntington's disease come together to support one another, find vital resources and share their journeys so that

care for HD improves as quickly as possible," said **Louise Vetter, President and CEO of the Huntington's** Disease Society of America.

To access the platform, visit HDSA.org/PLM



31 Days, 31 Stories



HDSA Reintroduces HD Parity Act

In March 2021, the Huntington's Disease Society of America announced that **Senators Kirsten Gillibrand** (D-NY) and **Dr. Bill Cassidy** (R-LA), along with Representatives Adam Kinzinger (R-IL) and Bill Pascrell, Jr (D-NJ) have reintroduced the Huntington's Disease Parity Act (\$ 868 / HR **PASS THE** 2050). The HD Parity Act will waive the **HD PARITY** two-year Medicare waiting period, as well as waive the 5-month benefit waiting period for individuals with Huntington's disease (HD) accessing Social Security Disability Insurance (SSDI).

To learn more please visit HDSA.org/takeaction.





Rep. Adam Kinzinger (R-IL)



Rep. Bill Pascrell, Jr (D-NJ)

Kala Booth Testifies in Front of Congress

The Huntington's Disease Society of America applauded the House Energy and Commerce

> Subcommittee on Health for holding a vitally important hearing on July 29th that put a spotlight Huntington's disease. Kala Booth, an HD patient

and caregiver, testified to the distinct challenges of living with HD, its multi-generational impact, and the importance of improving access to vital health benefits as outlined in the bipartisan Huntington's Disease Parity Act.



On July 29th, the House Energy and Commerce Subcommittee on Health heard the testimony given remotely by HD patient and caregiver, Kala Booth (above) on the importance of the HD Parity Act.

May Is HD Awareness Month — #LetsTalkAboutHD

May Is HD Awareness Month, so #LetsTalkAboutHD! HDSA teamed up with members of the HD community to turn up the global volume to let the world know about this devastating brain disorder.



ACT

#GivingTuesday — November 30th

GING TUESDAY

>\$99,000

RAISED FOR HDSA—
THE MOST EVER!

With more than 250 donations from around the world, more than \$99,000 was raised to support HDSA on Tuesday, November 30th, #GivingTuesday — a global day of giving. This was the most funds raised for an HDSA Day of Giving ever!

Scott Porter Invitational: HeroClix for HD





Simi Fehoko Wears HDSA Cleats During the NFL's #MyCauseMyCleats Campaign

Dallas Cowboy **Simi Fehoko** supported the fight against HD by wearing custom HDSA cleats during

the NFL's #MyCauseMyCleats
Campaign during a game against
the New Orleans Saints on
December 2nd. Simi, who comes
from an HD family, paid tribute to
his grandmother who passed away
from HD. This marks the second
time an NFL player wore cleats to raise
awareness of HD. Aaron Donald of the Los Angeles Rams
participated in the initiative in 2018. Thank you Simi!
And congrats for the win over the Saints!





HDSA Founder's Day — September 18th

Each year, HDSA honors Marjorie Guthrie's legacy to "do something" during the HDSA Founder's Day campaign on September 18th. In 2021, the initiative raised more than \$32,866 to ensure that our social workers, support groups, education programs and critical HD research continue to help improve the lives those affected by HD.





Ginny & Georgia Reunion

With help from HDSA's dear friend **Scott Porter**, the castmates and creators of the hit Netflix series, *Ginny & Georgia* participated in a virtual reunion fundraiser for HD. The much-anticipated event raised nearly \$5,000 and received more than 100,000 views on HDSA's YouTube channel.



William H. Macy Hosts Virtual Bourbon Tasting Event to Support HDSA

On June 17th, stage and screen star **William H. Macy** hosted a virtual bourbon tasting event to support HDSA which raised

New York City Marathon Team Raises More Than \$64,000

Eighteen runners from across the United States the figure participated in the 50th Anniversary running of the **TCS New York City Marathon** and helped raise more than \$64,000 to support the Huntington's Disease Society of America.

"We can't thank our runners enough for all their hard work to not only fundraise, but also for their willingness to take on the NYC Marathon to support the fight against Huntington's disease," said HDSA's President and CEO **Louise Vetter.** "Each step they took through the five boroughs was a tribute to

the strength of the HD community and helped to raise awareness for this devastating, rare brain disease."

In addition to the generous donors supporting the HDSA runners, participation in the TCS New York City Marathon was made possible in part by sponsorship from **Eisner Amper LLC.**



>\$64,000

RAISED FOR HDSA

Virtual Seventh Annual Freeze HD Raises More Than \$212,000

On Saturday, October 16th, the stars came out to support the Huntington's Disease Society of America at the **Seventh Annual Freeze HD** event. Hosted live from Los Angeles by **Kate Miner, Scott Porter** and **Jason Ritter,** more than \$212,000 was raised to support HDSA's mission to improve the lives of

families affected by Huntington's disease, a rare, inherited brain disease.

FREEZE HD

>\$212,000

RAISED FOR HDSA

"Being virtual for the second straight year, allowed Freeze HD to share the story of HD families to a global audience while generating much-needed funds to support HDSA's support programs," said HDSA's

President and CEO Louise Vetter.

"It was a special night for HD families, and we are grateful to all who donated, sponsored, and performed and to our incredible hosts Kate, Scott and Jason for putting together an amazing show."

To learn more about Freeze HD, please visit HDSA.org/freezehd.





GOLD SPONSOR

uniQure

SILVER SPONSORS

Fade Into The Bright and Milkman/Marron Foods

BRONZE SPONSORS

Tammy & Jessica Cain, CPM, Fake Empire, Kelsey & Scott Porter and The Sypek Group

BAR SPONSORS

After Hours Theatre Company, Gersh Agency, Philip Koosed, The Impact Agency, Rotary Club Studio City-Sherman Oaks, Torn2rbns Productions Inc and Twelve Rivers Realty

FRIEND SPONSORS

Big Yellow Dog Music; Boothatron Solutions; Brillstein Entertainment Partners; Nassif Dow; Force Environmental Inc.; Lazarus, Goldbarg & Associates; Theresa O'Hern; Pathfinder Partners; Laurayne Ratner; Carly Ritter; Alyssa Schwartz; and Eric & April Williams.

Thank you to the Freeze HD committee for all their hard work and commitment to making Freeze HD a success:

Jessica Cain, Kipenzi Chidinma,
Blake & Jenne Coler-Dark, David Cooper,
Brian Logan Dales, Christopher & Lisa Davis,
Jessica Etting, Matt & Courtney Hamilton,
Gentille Koosed, Justin & Kate Miner,
Marianna Palka, Scott & Kelsey Porter,
Carly Ritter, Jason Ritter and
Alana Yankowitz.

Virtual 36th Annual HDSA Convention Welcomes Thousands from Around the World

Nearly 2,100 registrants from more than 33 countries participated in the **Virtual 36th Annual HDSA Convention** June 10th to 13th. The four-day virtual event featured world-class presentations on the latest in Huntington's disease research and care. Despite not being able to meet in-person, the Virtual HDSA Convention allowed guests to connect virtually through

the HDSA Convention app and visit the Virtual Exhibit Hall.



Huntington's Disease
Society of America

HDSA NATIONAL AWARDS

PERSON OF THE YEAR AWARD

Yvonne Sweeten

MARJORIE GUTHRIE AWARD

E.J. Garner

WOODY GUTHRIE AWARD

Doug Schulte

YOUTH/JHD AWARD

Jenna & Gia Mannone

CHAPTER OF THE YEAR AWARD

HDSA Illinois Chapter

AFFILIATE OF THE YEAR AWARD

HDSA San Francisco Bay Area Affiliate

Recorded sessions from the Virtual 36th Annual HDSA Convention are available at www.HDSA.org/convention.



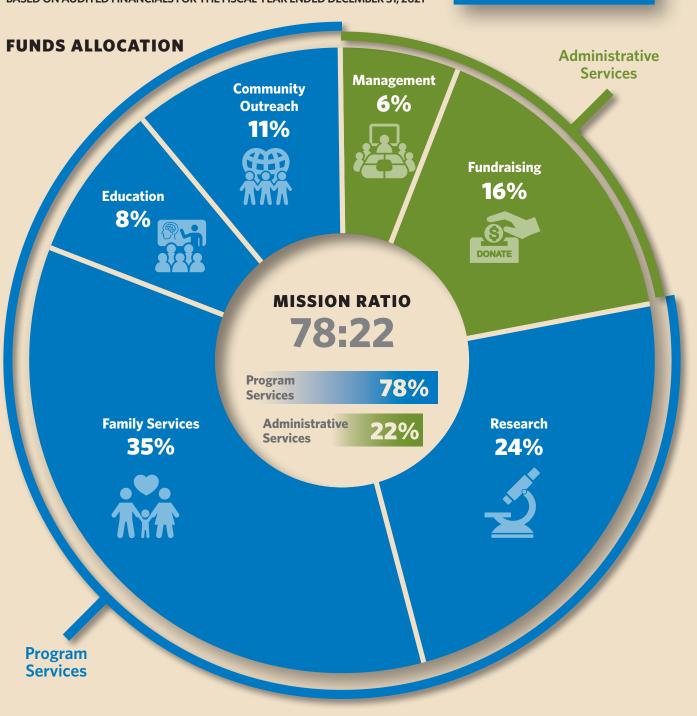
Financials

Your HDSA Dollars at Work

BASED ON AUDITED FINANCIALS FOR THE FISCAL YEAR ENDED DECEMBER 31, 2021

OVERVIEW

- TOTAL 2021 REVENUE \$12.9 Million
- HDSA CENTER OF EXCELLENCE GRANTS
 \$1.55 Million
- RESEARCH GRANTS\$1.27 Million
- SOCIAL WORKERS \$587,000



Statements of Financial Position

AS OF DECEMBER 31, 2021 AND 2020

| | 2021 | 2020 |
|---|---------------|--------------|
| SSETS | | |
| Cash and cash equivalents | \$ 11,228,810 | \$ 9,339,030 |
| Pledges and contributions receivable, net | 2,598,770 | 1,133,748 |
| Investments | 2,503,034 | 2,310,097 |
| Prepaid expenses and deposits | 193,969 | 154,406 |
| Property and equipment, net | 28,993 | 35,148 |
| Website costs, net | 18,343 | 39,529 |
| Total Assets | 16,571,919 | 13,011,958 |
| ABILITIES | | |
| Accounts payable and accrued expenses | 120,126 | 214,836 |
| Accrued compensation | 263,269 | 294,228 |
| Grants payable, net | 1,364,174 | 1,283,055 |
| Event revenue received in advance | 61,177 | 17,800 |
| Paycheck Protection Program loan payable | | 634,692 |
| Deferred rent obligation | 103,731 | 114,721 |
| Obligation under capital lease | | 3,734 |
| Total Liabilities | 1,912,477 | 2,563,066 |
| ET ASSETS | | |
| Without donor restrictions | | |
| Undesignated | 9,010,574 | 4,114,838 |
| Board-operating reserve | 1,808,203 | 1,805,969 |
| | 10,818,777 | 5,920,807 |
| With donor restrictions | | |
| Purpose restrictions | 1,235,715 | 4,178,135 |
| Time-restricted for future periods | 2,354,950 | 99,950 |
| Perpetual in nature | 250,000 | 250,000 |
| | 3,840,665 | 4,528,085 |
| Total Net Assets | 14,659,442 | 10,448,892 |
| | | |

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, 2021 WITH SUMMARIZED FINANCIAL INFORMATION FOR 2020

| PPORT & REVENUE | 2021 | 2020 |
|--|------------|------------|
| Public donations | 6,095,983 | 3,116,252 |
| Foundation grants and corporate contributions | 2,330,828 | 3,115,452 |
| Federated campaign | 244,545 | 246,913 |
| Special events (net of direct benefit to donors of \$212,622 and \$618,196 in 2020 and 2019, respectively) | 3,361,360 | 2,254,487 |
| Investment (losses) earnings, net | 9,661 | 21,904 |
| Donated services and materials | 173,753 | 132,439 |
| Gain on Paycheck Protection Program loan forgiveness | 634,692 | _ |
| Other income | 87,656 | 83,178 |
| Total support and revenue before net assets released from restrictions | 12,938,478 | 8,970,625 |
| Net assets released from restrictions | _ | _ |
| Total Support and Revenue | 12,938,478 | 8,970,625 |
| Program services: | | |
| | | |
| Research | 2,052,914 | 2,102,371 |
| Family services | 3,005,423 | 3,083,605 |
| Education | 704,513 | 761,119 |
| Community outreach | 972,726 | 1,023,900 |
| | 6,735,576 | 6,970,995 |
| oporting services: | | |
| Management and general | 570,858 | 592,598 |
| Fundraising | 1,421,494 | 1,217,994 |
| | 1,992,352 | 1,810,592 |
| Total Expenses | 8,727,928 | 8,781,587 |
| ange in net assets | 4,210,550 | 189,038 |
| t assets - beginning of year | 10,448,892 | 10,259,854 |
| t Assets - End of Year | 14,659,442 | 10,448,892 |

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.

Thank You HDSA Donors!

Thank You to Our Donors for Their Generous Support of HDSA With \$1,000 or More

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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

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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.

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