### Huntington's Disease Society of America

# CARE. CURE. COMMUNITY.

### 2022 Annual Report

37" ANNUAL HDSA CONVENTION

### CONTENTS

#### Care. Cure. Community. Leadership Letter...

<b>CARE</b>
HDSA Centers of Excellence2
By the Numbers — HDSA's Impactful Social Work4
<b>CURE</b>
Human Biology Project Fellowships6
Donald A. King Summer Research Fellowships7
Berman-Topper HD Career Development Fellowship8
<b>COMMUNITY</b> 9
37 <sup>th</sup> Annual HDSA Convention10
8 <sup>th</sup> Annual Freeze HD Gala12
New York City Marathon13
Financials14
Thank You Donors18
Special Thanks26
Planned Giving27
Volunteer Opportunities28
HDSA LeadershipIBC
HDSA Contacts & ServicesBC



#### Dear Friends,

Care. Cure. Community. These three simple words represent everything that inspires the Huntington's Disease Society of America and describes our mission work.

In 2022 the HDSA Board launched a new Strategic Plan defined by these 'three C's' and infused with the urgency and clarity of HD families. HDSA exists to ensure that everyone impacted by HD has access to the highest quality of **care**, to accelerate the development of treatments (cures) for HD, and to support and empower the HD family (community).

Families are HDSA's 'why' and these goals are the 'how' for achieving our mission: to improve the lives of people with Huntington's disease.



This year's Annual Report recognizes our

discipline and impact in the areas of Care, Cure and Community. From our cornerstone programs like the HDSA Centers of Excellence and the Annual HDSA Convention to our diverse research grant portfolio and community awareness campaigns, HDSA's mission work continued to expand and evolve in 2022, so that we can do more for more families.

For the first time ever, the HDSA Annual Report is truly a multi-media experience! In addition to the photos and information that showcase the accomplishments of the HDSA community, we invite you to click on the linked videos on the pages to hear personal stories from families, clinicians and scientists whose lives have been changed by HDSA. Each of the individuals featured in these vignettes is a hero, helping to keep the HD community strong and bring our mission to life. We are so grateful.

HDSA exists because of the thousands of volunteers, donors and partners who continue



to follow Marjorie Guthrie's call to action: to "do something" about HD. Every day they give their time and talent and their generous donations fund everything we do. In HDSA Chapters and Affiliates, at HD Clinics, in laboratories, and through networks of community services with our social workers and support groups, the HD families are helping to bring more Care forward, find the Cure and support our HD Community.

We challenge you to let the people in your HD community know how grateful you are for their



Louise Vetter

service, by sending a note to info@hdsa. org or posting a message on social media. At HDSA, family is everything, and we look forward to sharing your notes of gratitude.

As we head into the heart of 2023, HDSA is working to launch new programs, services, research projects and community events to increase our ability to provide help and cultivate hope. Check out **HDSA.org** and follow us online to stay up to date, and we hope to see you at an HDSA event soon!

Thank you for your continued partnership in the fight against HD.

Gratefully,

Jeresa Sraji

Teresa Srajer Chair, HDSA Board of Trustees

Juin Vetr

Louise Vetter President & CEO



#### HDSA Awards Nearly \$1.9 Million to Network of Fifty-Five HDSA Centers of Excellence

Huntington's Disease

Center of Excellence

**HDSA AWARDED** 

**TO THE HDSA CENTERS** 

**OF EXCELLENCE PROGRAM** 

Early in 2022, the Huntington's Disease Society of America announced that fifty-five outstanding Huntington's disease care facilities are being awarded the designation of HDSA Centers of **Excellence** for 2022. In addition to the 55 grant funded clinics, ten regional partner sites were also named ensuring expert HD care at 65 distinct medical facilities in 35 states across the

#### nation. In 2022, \$1,896,333 has been awarded to the HDSA Centers of Excellence program.

The HDSA Centers of Excellence are multi-disciplinary care teams with expertise in Huntington's disease that share an exemplary commitment to providing comprehensive care for this complex, hereditary, neurodegenerative disease. The expansion from 54 sites in 2021 to 55 sites in 2022 comes from

the addition of Oregon Health & Science

**University** as the newest HDSA awarded clinic. Launched in 1998, the HDSA Center of Excellence network has grown from 20 sites as recently as 2015.

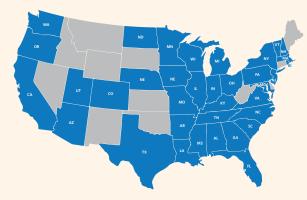
In addition, the HDSA Center of Excellence network added three new designated Partner Sites: St. Luke's University Health Network (Bethlehem, PA), Selkirk Neurology (Spokane, WA), and Central Florida Center for Huntington's **Disease** (Winter Park and Orlando, FL), bringing a total of ten Partner Sites nationwide. The other seven Partner Sites include: University of South Alabama (Mobile, AL), Kaiser Permanente (CA), Covenant Medical Group Neurology (Lubbock, TX), Texas Movement Disorders Specialist PLLC, (University of Texas Health San Antonio), Cole Neuroscience Center (University of Tennessee Medical Center) and University of **Tennessee** (Erlanger Medical Center).

"The Huntington's Disease Society of America is committed to supporting the best possible care for families affected by Huntington's disease," said Teresa Srajer, Chair of HDSA's National Board of Trustees and Director of the HDSA Center of Excellence at The University of Alabama, Birmingham. "Continuing to expand the reach of the HDSA Centers of Excellence

> network allows more families across the country to have access to these world-class clinics."

The HDSA Centers of Excellence provide an elite team approach to Huntington's disease care and research. Patients benefit from expert neurologists, psychiatrists, therapists, counselors and other professionals who have extensive experience working with families affected by HD and

who work collaboratively to help families plan the best HD care program throughout the course of the disease. Applications to become an HDSA Center of Excellence are open to all clinics in the United States who share HDSA's commitment to high-quality, comprehensive care and access to clinical research.



HDSA Centers of Excellence network includes 55 clinics and ten partner sites in 35 States and the District of Columbia.

#### The 2022 HDSA Centers of Excellence Grantees

Albany Medical College (NY) Barrow Neurological Institute (AZ)

Beth Israel Deaconess Medical Center (MA)

Cleveland Clinic (OH)

Columbia Health Sciences/NYS Psychiatric Institute (NY)

Duke University (NC)

Emory University (GA)

MedStar Georgetown University Hospital (DC)

Hennepin Health Care (MN)

Henry Ford Hospital (MI)

Indiana University

Johns Hopkins University (MD)

Massachusetts General Hospital

Medical University of South Carolina

Northwestern University (IL)

Ochsner Health System (LA)

Ohio State University

Oregon Health & Science University\*

Rocky Mountain Movement Disorders Clinic (CO)

Rowan University School of Medicine & Rutgers University RWJ Medical School (NJ)

Rush University Medical Center (IL)

Sanford Health (ND)

Stanford University (CA)

Stony Brook University Hospital (NY)

University of Alabama, Birmingham

• Partner Site: University of South Alabama

University of California, Davis Medical Center

Los Angeles

San Diego

University of California, San Francisco

University of Florida

University of Iowa

University of Kansas

Medical Center

Medical Center

Medical Center University of Pennsylvania

Health Network, Bethlehem, PA\*

University of Pittsburgh Medical Center (PA)

University of Rochester (NY) University of South

Carolina School of Medicine

• Partner Site: Central Florida

or Partner Sites for 2022.



**CLICK HERE OR SCAN QR CODE FOR VIDEO:** What Is Different About an HDSA Center of Excellence?

- University of Arkansas
- University at Buffalo (NY)
- Partner Site: Kaiser Permanente (CA)
- University of California, Irvine
- University of California,
- University of California,
- University of Cincinnati (OH)
- University of Colorado
- University of Louisville (KY)
- University of Miami (FL)
- University of Mississippi
- University of Nebraska
- Partner Site: St. Luke's University
- University of South Florida Center for Huntington's Disease, Winter Park and Orlando, FL\*
- \* NOTE: Blue text indicates newly designated HDSA Center of Excellence

University of Texas Health Science Center at Houston, McGovern Medical School

- Partner Site: Covenant Medical Group Neurology, Lubbock, TX
- Partner Site: Texas Movement Disorders Specialist, PLLC
- Partner Site: University of Texas Health San Antonio

University of Utah

University of Vermont, Frederick Binter Center for Parkinson's Disease and Movement Disorders

University of Virginia

- University of Washington (WA)
- Partner Site: Selkirk Neurology, Spokane, WA\*

University of Wisconsin

Vanderbilt University Medical Center (TN)

- Partner Site: Cole Neuroscience Center, University of Tennessee Medical Center
- Partner Site: University of Tennessee, Erlanger Medical Center

Virginia Commonwealth University

Washington University School of Medicine (MO)



Five HDSA Centers of Excellence celebrated 25 years of outstanding service. Pictured are: Teresa Srajer, Chair, HDSA Board of Trustees; Mary Jones, Johns Hopkins University/ Hospital (MD); John Smith, Rocky Mountain Movement Disorders (CO): Mary Jones. Hennepin Health Care (MN): Louise Vetter. HDSA President & CEO; Mary Jones, University of Rochester (NY); Mary Jones, Columbia University Neurological Institute (NY).

CARE 3

### 

#### By the Numbers — HDSA's Impactful Social Work in 2022

#### **EDUCATION**



HDSA's educational webinars generated 3,166 views on our YouTube Channel in 2022.



**HDSA** webinars were seen live by 535 attendees in 2022

#### **ADVOCACY**



Approximately 4,500 messages (includes emails, phone calls, tweets) were sent to Congress from HD impacted families.

#### **DISABILITY ASSISTANCE**



HDSA advocated for 341 unique contacts with people living with HD and their families. Over 100 hours were spent communicating directly via phone calls and emails. HDSA's intervention resulted in 11 documented cases of Huntington's disease patients being awarded **Disability Benefits.** 

#### YOUTH & YOUNG ADULT PROGRAMS AND SERVICES

CARE

4

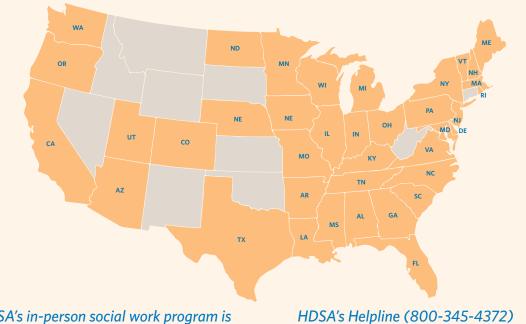


Social workers provided over 700 hours of services dedicated to youth and young adults including direct services, programs, and professional consultations.









HDSA's in-person social work program is availabe in 38 states. Nationwide, online services can be found at HDSA.org.



**CLICK HERE OR SCAN QR CODE FOR VIDEO:** What Is an HDSA Support Group?

#### NATIONWIDE SUPPORT SERVICES

SOCIAL Worker Hours	Over 6,600 hours of <b>social</b> <b>workers provided services.</b> Over half that time included direct services — individual services, HDSA Helpline, and support groups.
RT 'S	HDSA sponsored 136 in-person Community Support Groups nationwide. In addition, there were 10 online HDSA Support Groups available.
RS OF Apy N By Ell & Hdsa	HDSA, in partnership with leading telehealth company <b>American</b> <b>Well</b> <sup>®</sup> , offered free online therapy to people affected by Huntington's disease.

is availabe Monday-Friday, 9 a.m. to 5 p.m., EST.

### **2022 Human Biology Project Fellowships**

CURE

In October of 2022, thanks to your investment in HD Research, HDSA awarded six research grants under the Society's largest research initiative, the **HDSA** Huntington's Disease Human Biology Project. Totaling more than \$886,785, these grants represent HDSA's patient-centric research focus which brings basic and clinical researchers together to facilitate Hunting-



ton'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, Hungary, Spain, and the United Kingdom.



Ines Bras, PhD Postdoctoral Scholar University of Central Florida **Non-Invasive HD Biomarkers** 



Lea Danics, PhD Postdoctoral Scientist Semmelweis University (Hungary) Identifying Novel Therapeutic Targets in HD



Paul Dennis, MFA Professor and Chair, Dance Department Hunter College, CUNY **Dance for Huntington's Disease** 



Maria Rosario Fernandez-Fernandez, PhD Senior Scientist FINBA-ISPA (Spain)

**Restoring Protein-Building** Machinery



**Kilian Hett, PhD** Postdoctoral Research Fellow Vanderbilt University Studying the Flow of **Cerebrospinal Fluid** 

CURE

6



Mitsuko Nakajima, **MBChB**, MPhil Clinical Research Fellow University College London **Visualizing Brain Changes** in Pre-Symptomatic HD



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. 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.

#### The 2022 recipients of the Donald A. King Summer Research Fellowships were:



Manasa Chillarige (University of Pittsburgh) will, under the mentorship of Diane Carlisle, PhD, study whether activation of a specific protein pathway can protect brain cells from the negative effects of stress brought on by HD.

**Carly Fisher** (The Ohio State University) will work in the lab of Richard Fishel, PhD, to determine the role of FAN1, a DNA mismatch repair protein, in regulating CAG repeat expansion in HD.

CURE





**CLICK HERE OR SCAN QR CODE FOR VIDEO:** What Should We Know About **HDSA-Funded Research?** 

#### **2022 Donald A. King Summer Research Fellowships**

#### **Carolina Gomez Casas**

(University of Massachusetts Medical School) will study how a CRIPSPR-Cas9 system may be used to reduce CAG expansions in the mutated huntingtin gene under the mentorship of Michael Brodsky, PhD.

#### **Anthony Ventimiglia**

(The Ohio State University) will study the role of MLH1-PMS1, a protein complex that plays a role in DNA mistmatch repair, in regulating CAG repeat expansion in HD in the lab of Richard Fishel, PhD.

Katherine Vinski (University of Pittsburgh) will work in the lab of Diane Carlisle, PhD, to study how crosstalk between two protein pathways affects stress response in HD and to determine whether the pathways can be regulated to minimize negative effects.









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

**2022 Berman-Topper Family** 

HD Career Development Fellowship

Dr. Sara Sameni

support future generations 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 of their long-term career plans. Since its 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 Dr. Sara Sameni of the Salk Institute for Biological Studies in La Jolla, CA, as the 2022 Berman-Topper Fellow.





# Huntington's Disease Society of America

800-345-HD5A

hdsa.org



#### 37<sup>th</sup> Annual HDSA Convention Atlanta, Georgia

On June 9<sup>th</sup>-11<sup>th</sup>, the Huntington's Disease Society of America hosted the **37<sup>th</sup> Annual HDSA Convention** in Atlanta, Georgia at the Atlanta Marriott Marquis. **The event marked the first time an HDSA Convention featured in-person attendees since 2019**. The Convention welcomed 527 in-person attendees and more than 800 virtual attendees from around the globe in more

than 14 countries. All participants were also able to download the free HDSA Convention app which allowed them to connect with other attendees, ask questions during sessions, get updates and much more.

"It was amazing to bring the HD community together again," said **Louise Vetter,** HDSA's President & CEO. "Despite limiting the number of in-person attendees, the magic and one-of-a-kind energy of the HDSA Convention was certainly present. Living with a rare disease can be

isolating, so the togetherness of Convention is a powerful weapon in the fight to improve the lives of everyone affected by Huntington's disease."

On day one of the HDSA Convention, in-person attendees enjoyed the annual **Team Hope Walk** around the streets of Atlanta followed by a Welcome Reception with great food and music. The second day began with a comprehensive and very entertaining research update during the Opening Ceremony from **Drs. Jeff Carroll** and **Ed Wild** from **HDBuzz.net.** Sessions were conducted throughout the day led by HD experts.

The day's activities included the Volunteer Awards Luncheon during which, the following were recognized for their outstanding work:



**SOCIAL MEDIA AWARD:** HDSA Los Angeles Chapter

OUTSTANDING ACHIEVEMENT IN ADVOCACY AWARD: Washington State Chapter

OUTSTANDING ACHIEVEMENT IN BOARD DEVELOPMENT: Massachusetts & Rhode Island Chapter

OUTSTANDING ACHIEVEMENT IN EDUCATION OR FAMILY SERVICES: Kentucky Chapter

OUTSTANDING ACHIEVEMENT IN FUNDRAISING: Central Ohio Chapter

AFFILIATE OF THE YEAR AWARD: HDSA Omaha Affiliate

**CHAPTER OF THE YEAR AWARD:** HDSA Northeast Ohio Chapter

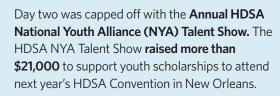








COMMUNITY



On the third and final day of the Convention began with the **Research Forum** and an amazing keynote from **Dr. Sarah Tabrizi** of University College London (UCL). After the final sessions, all those in attendance (both in-person and virtual) took part in the **HDSA Convention Awards Dinner & Gala** which included the emotional **Candle Lighting Ceremony** to honor the HD community.

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

The following individuals received HDSA's National Awards for their outstanding service and achievements:



**Excellence in Care** Jessica Marsolek (Minnesota)



Youth Award Ashley Pesi (Pennsylvania)



Research Award Dr. Sarah Tabrizi (University College London)



Marjorie Guthrie Award Heather Thurgood Wilmoth (Mississippi)



Woody Guthrie Award Kinser Cancelmo (Massachusetts)



Person of the Year Jesse Lis (Ohio)







#### **CLICK HERE OR SCAN QR CODE FOR VIDEO:** 37<sup>th</sup> Annual HDSA Convention Atlanta, GA

The Huntington's Disease Society of America would like to thank the following sponsors for making the 37<sup>th</sup> Annual HDSA Convention an amazing success:

#### **PRESENTING SPONSORS**

- Genentech
- Teva Pharmaceuticals

#### **GOLD SPONSOR**

uniQure

#### **GOLD NON-PROFIT SPONSOR**

Enroll-HD/CHDI

#### **SILVER SPONSORS**

- Neurocrine Biosciences
- Novartis
- Sage Therapeutics

#### **BRONZE SPONSORS**

- MassMutual SpecialCare
- Picnic Health
- ▶ PTC Therapeutics
- Wave Life Sciences

#### **FRIEND SPONSORS**

- Archcare
- AskBio
- Broda
- Prilenia
- Spark Therapeutics







#### **CLICK HERE OR SCAN OR CODE FOR VIDEO:** 8<sup>th</sup> Annual Freeze HD (2022 Recap)



#### **THANK YOU SPONSORS!**

**GOLD SPONSOR** uniQure SILVER SPONSORS **The Eisner Foundation** Seth Green **Gentile & Terry Koosed Torn2Ribbons BRONZE SPONSORS The Burstein Company Fake Empire The Gersh Agency Marron Foods** Netflix **Kelsey & Scott Porter Nancy Morgan Ritter The Sypek Group BAR SPONSORS After Hours Theater Company Joanie Bernstein Boothatron Solutions Brillstein Entertainment Partners** Jessica Cain **Blake & Jenne Coler-Dark Custom Comfort Mattress** Hamilton Land Development, Inc. Candace Jackson Tamar & Phil Koosed **Carly Ritter Shawn Smith Doug Zatar** 

#### SPECIAL APPEARANCES

Ali Ahn, Wilson Bethel, Rachel Bilson, EJ Bonilla, Jason Canela, Debbie Gibson, Eric Edelstein, Debra Fisher, Zach Gilford, Seth Green, Jeremy Konner, Simon Helberg Bryce Dallas Howard, Emma Hunton, Tricia LaFache, Sean Maguire, Chris Marquette, Tanya Memme, Dash Mihok, Nora-Jane Noone, Patton Oswalt, Judge Reinhold, Homer Simpson **Amy Yasbeck and many more!** 

After two years of virtual programs, the popular Freeze HD event to support the Huntington's Disease Society of America returned in person on Saturday, October 22, 2022 at

**Eighth Annual Freeze HD Gala** 

**S208.**0

GALA RAISED OVER

IN 2022

the Avalon in Hollywood and raised more than \$208,000. The event honored Jason Ritter and the Ritter Family for their incredible support in the fight against Huntington's disease. Freeze HD was created by the Ritter

family and Marianna Palka in 2014. Jason, Nancy Morgan Ritter, Tyler Ritter and Lelia Parma were on stage to accept the honor. Marianna Palka and Lucy Walker introduced the honorees after showing the trailer of the 2014 HBO Films documentary, The Lion's Mouth Opens. The powerful short film, directed by Walker, followed Marianna's HD testing journey and featured Jason and Bryce Dallas Howard.

The Eighth Annual Freeze HD was hosted by Broadway star Meredith **Patterson** (42<sup>nd</sup> Street) and **Dustin Brayley** (Trans-Siberian Orchestra) who performed several acts with their

sons, Billy and Maxwell. Actor Scott Porter also performed musical numbers featuring two-time Grammy nominee Matt Beckley.

> "Freeze HD is much more than a charity event for families affected by Huntington's disease. It is a call to action to stop this devastating brain disease in its tracks with more awareness, care and science," said Louise **Vetter,** HDSA's President

and CEO. "Since its visionary launch nine years ago by the Ritter family and Marianna Palka, this annual event has raised more than \$1.7 million to support HDSA's programs of help and hope. We are grateful to our host committee, sponsors and the Los Angeles community who join us in celebrating the strength of HD families while we fight for a healthier tomorrow."

The much-anticipated red carpet event featured an incredible auction, live entertainment, celebrity meet and greet, surprise guests, and an exclusive VIP Afterparty.



Twenty-three runners from across the United States and Canada participated in the TCS New York City Marathon on Sunday, November 6, 2022 to support the Huntington's Disease

Society of America. By race day, the team had raised \$93,760. Donations continued after the event and a total of \$107.000 was received!

"We can't thank our runners enough for their commitment to fighting Huntington's disease," said Louise Vetter, President and CEO of HDSA. "The funds raised will go towards supporting

HDSA's mission to improve the lives of everyone with HD and their families."







#### **TCS New York City Marathon 2022**

Sean Riddle recorded the team's fastest finish completing the 26.2-mile marathon in an impressive 4 hours and 4 minutes. Thank you **EisnerAmper LLP** for serving as this year's team jersey sponsor.



Thank you Team HDSA: **Emalee Blumhagen** (NY), **Amy Bond** (CA), Craig Bond (CA), Teresa Brooks (IA), Jordan Brown (TN), Craig Calo (NY), Kerry Cavanagh (MA), Samantha Cox (IL), Andrea Doepker (OR), Haley Falkenberry (NY), Lauren Hinkley (Washington, DC), Marie Elena Howe (PA), Hannah **Joeckel** (TX), **Brett Kincade** (TX), Todd Marentette (Wheatley,

Ontario), Jessica Marsolek (MN), Arturo Pardavila III (NJ), Jeff Pucciarelli (FL), Sean Riddle (CT), Jon Rink (MI), Bianca Schwarz (UT), Jaylen Sheldon (LA) and Susan Wooten (IL).



# FINANCIALS —

Huntington's Disease Society of America

14



**Community Outreach** 9%

**SUPPORT AND REVENUE** 

• Total 2022 Revenue:.....\$ 11.3 Million

**TOP FOUR MISSION INVESTMENTS** 

- HDSA Center of Excellence Grants:...\$ 1.86 Million
- Research Grants: .....\$ 992,995
- Social Workers:.....\$ 615,994
- Education: .....\$ 1,648,297

#### HDSA Dollars at Work

**FUNDS ALLOCATION** 

#### **MISSION RATIO**



Program Services:.....73%

Administrative Services:.....27%



#### **Statements of Financial Position**

#### AS OF DECEMBER 31, 2022 AND 2021

	2022	2021
ISETS		
Cash and cash equivalents	\$ 12,704,109	\$ 11,228,810
Pledges and contributions receivable, net	609,670	2,598,770
Investments	3,920,368	2,503,034
Prepaid expenses and deposits	191,683	193,969
Right-of-use asset	711,837	
Property and equipment, net	18,129	28,993
Website costs, net	3,514	18,343
Total Assets	18,159,310	16,571,919
Accounts payable and accrued expenses	225,956	120,126
ABILITIES		
Accrued compensation	281,587	263,269
Grants payable, net	980,273	1,364,174
Event revenue received in advance	34,184	61,177
Paycheck Protection Program loan payable		
Deferred rent obligation		103,731
Lease liability	797,692	
Total Liabilities	2,319,692	1,912,477

	1	- / /
With donor restrictions		
Purpose restrictions	3,170,904	3,235,715
Time-restricted for future periods	239,950	354,950
Perpetual in nature	250,000	250,000
Total net assets with donor restrictions	3,660,854	3,840,665
Total Net Assets	15,841,135	14,659,442
Total Liabilities And Net Assets	18,159,310	16,571,919

**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, 2022 WITH SUMMARIZED FINANCIAL INFORMATION FOR 2021

JPPORT & REVENUE	2022	2021
Public donations	3,928,995	6,095,983
Foundation grants and corporate contributions	2,561,277	2,330,828
Federated campaign	205,863	244,545
Special events (net of direct benefit to donors of \$553,989 and \$360,708 in 2022 and 2021, respectively)	4,030,332	3,361,360
Investment (losses) earnings, net	20,318	9,661
Donated services and materials	339,992	173,753
Gain on Paycheck Protection Program loan forgiveness		634,692
Returned grants	121,808	
Other income	88,623	87,656
Total support and revenue before net assets released from restrictions	11,297,208	12,938,478
Net assets released from restrictions		
Total Support and Revenue	11,297,208	12,938,478
PENSES Program Services:		
Research	1,518,391	2,052,914
Family services	3,300,739	3,005,423
Education	1,648,297	704,513
Community outreach	901,210	972,726
Total program services	7,368,637	6,735,576
oporting Services:		
Management and general	820,000	570,858
Fundraising	1,928,395	1,421,494
Total supporting services	2,748,395	1,992,352
Total Expenses	10,117,032	8,727,928
ange in net assets	1,180,176	4,210,550
t assets - beginning of year	14,659,442	10,448,892
t Assets - End of Year	15,839,618	14,659,442

**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!

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

Anonymous (4) Joseph Adam Edward Adams Judith Addis Tina Aguilar Allam Al -Turk Kamran Alam Jeremiah Alexander Nancy R. Alfonso Angela and Bernard Allen Brenda Allen Wade Allred Tom Amodio Jenn Anderson Joanna Anderson Claudia Anderson Margaret Anderson Lynn Anderson Mary Anderson Vanessa Andrews Paul Andriot Agnes M. Arnold Diane Atkins Michael Ayers Lucinda Ayers Sand Bagoon, Ph.D. Koaki Bailey-Harris Toria Baker Norman Baldwin Leaf Ballast Jacqueline Ballwanz Monica (aka Lady Bard) Pat Barker Larry Barnhart Marylee Battaglia Cory Baughman Miles and Lisa Beacom Chelsea Beaulne Linda Becker Danny Bega, M.D. Brett Begemann Ashok Behl, M.D., FACC Elizabeth S. Bellamy Kristina Benner Justin Bennett Gudrun S. Bennett Karen Bennett Ashley Benton Ron Bergan Kathleen Bergeson Mark Berlinski Barbara Berman

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#### 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.

**26** 

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

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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.



**CLICK HERE OR SCAN** QR CODE FOR VIDEO: Why I Volunteer for HDSA

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With over 50+ volunteer led Chapters and Affiliates across the country our volunteers are spreading awareness through local advocacy efforts, as well as providing support and resources to their local community by organizing

events, such as our signature **Team Hope** Walks, HDSA & Me education days and support groups. <u>CLICK HERE</u> (HDSA.org/volunteer) or scan QR code at right) to find out how you can get involved!



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