Huntington's Disease
Society of America

HDSA 2024 ANNUAL REPORT

Together Towards Tomorrow

Reflecting on Progress, Empowering the Future

CARE

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COMMUNITY

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Chief Executive Officer

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Chief Mission Officer

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Director of Finance

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and Communications

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and Field Officer

LEADERSHIP LETTER

2024: A Year of Growth

Dear Friends of HDSA,

As we reflect on 2024, we are deeply grateful for the dedication and passion of our volunteers, advocates, and supporters. Your commitment makes it possible for the **Huntington's Disease Society of America (HDSA)** to deliver care, advance research, and make the HD community stronger and more connected.

This past year was a time of remarkable growth and renewed energy for HDSA's core pillars of **Care, Research,** and **Community.** New educational initiatives, expanded support services, groundbreaking research projects, and impactful community events all came to life thanks to your commitment. Your generosity and tireless efforts have strengthened our capacity to provide essential care for HD families today while fostering hope for a better future.

Care Without Boundaries

In 2024, we proudly grew the **HDSA Centers of Excellence network to 68 sites nationwide,** including 57 comprehensive care clinics and 11 regional partner locations. This **$2.1 million+ investment** ensures that HD families across the country have greater access to compassionate care from experts who understand the journey.

Research With Purpose

We invested **over $4 million into programs and services**, including the **HDSA Research Grants Program** and our flagship initiatives such as the **Berman-Topper Family HD Career Development Fellowship, HD Human Biology Projects,** and **Donald A. King Summer Research Fellowships.** These programs nurture the next generation of researchers and accelerate progress toward meaningful treatments.

A Community United

Our growing network of **120 social workers and 168 support groups**—both in-person and virtual — expanded critical support for families across the nation. And in June, the **39th Annual HDSA Convention in Spokane, WA** brought together **774 attendees** for three inspiring days of learning, connection, and community. From educational workshops to the National Youth Alliance Talent Show, the Convention highlighted the strength, resilience, and talent of the HD community.

Looking Ahead

As we look to the future, we know that our progress is only possible because of you. Together, we will continue to expand care, fuel research, and strengthen the HD community — bringing hope to families across the nation.

Though we come from many different paths, we stand together in our mission to improve the lives of everyone impacted by Huntington's disease. Thank you for your dedication and compassion, and for walking beside us as we support every family facing Huntington's disease.

One Vision. One Mission. One HDSA.

With gratitude,

Amy Gray
President and Chief Executive Officer, HDSA

Jenne Coler-Dark
Chair, HDSA Board of Trustees

CARE

HDSA Centers of Excellence

Expanding Hope: HDSA Grows Centers of Excellence Network to 68 Locations Nationwide

In a transformative step for families facing Huntington's disease (HD), the Huntington's Disease Society of America (HDSA) has awarded over $2.1 million in grants to fund 57 HDSA Centers of Excellence and name 11 additional regional partner sites, creating a national network of 68 expert care centers across 37 states and Washington, D.C.

The expansion — adding the **University of Connecticut Health Center** as the newest grant-funded site—represents a continuing commitment to improve access to comprehensive, family-focused HD care across the country.

Centers of Excellence: A Lifeline for Families

HDSA Centers of Excellence offer coordinated care through multidisciplinary teams that include neurologists, psychiatrists, social workers, genetic counselors, and therapists who specialize in HD. These teams work collaboratively to support patients and their loved ones from diagnosis through every stage of the disease. The model not only ensures access to expert care but also integrates research, clinical trials, and family resources.

Understanding HD's Impact

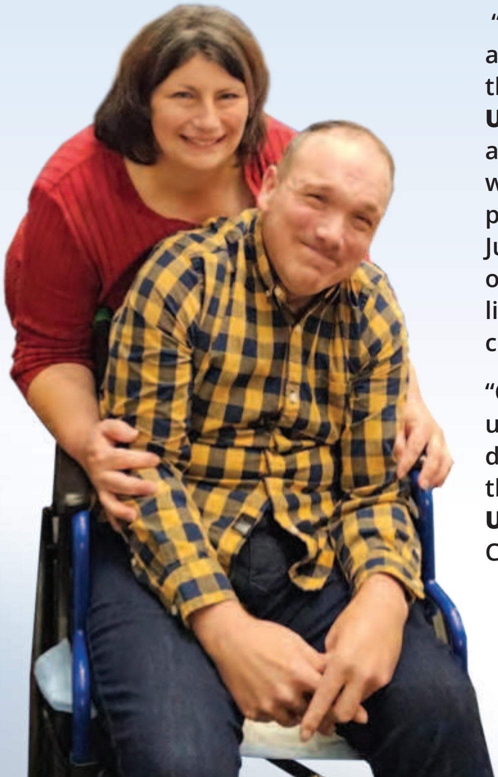
Huntington's disease is a fatal genetic disorder that causes the progressive breakdown of nerve cells in the brain. It impacts movement, behavior, and cognitive abilities, often during a person's prime working years. Today, an estimated 41,000 Americans are symptomatic, with over 200,000 at risk.

Often described as a combination of ALS, Parkinson's disease, and Alzheimer's, HD has no cure — making access to expert care essential.

HEATHER AND NATHAN'S STORY

HDSA Centers of Excellence Become an Extended Part of the Family

Meet **Heather Thurgood-Wilmoth**. She is a wife, a mother, and a caregiver to her loving husband, **Nathan**. Nathan was diagnosed with Huntingtonn's disease in 2016. Heather graciously explained how the support received from **HDSA Centers of Excellence (CoE)** has been deeply life-changing:



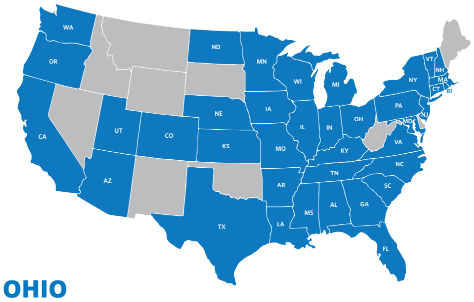
"We had, from the time that Nathan got diagnosed until our first appointment, the idea that Nathan was going to die tomorrow and that life was over. **Dr. Sung** and the **HDSA Center of Excellence at the University of Alabama** staff met us with such a positive disposition. He even advised us that we could keep him and the Center staff as a primary care doctor and primary care location. Just from that experience, when we walked out, we were not the same Heather and Nathan that walked in. It was like a weight had been lifted. That visit helped us first realize that Nathan could still have quality and quantity of life."

Huntington's Disease Society of America
Centers *of* Excellence

"COEs are like an extended part of our family that has a greater understanding of this disease. Center staff and procedures may be different, but if you are going to get the help that you need, that is the best place you can be. Now, with **Dr. Huang** at the **HDSA CoE at University of Mississippi Medical Center** and Dr. Sung at the HDSA CoE at UAB, we plan for the future but live for today."

The 2024 HDSA Centers of Excellence Network

**** Bold text indicates newly designated HDSA Center of Excellence for 2024.***



ALABAMA
University of Alabama, Birmingham
- *Partner Site: University of South Alabama*

ARIZONA
Barrow Neurological Institute

ARKANSAS
University of Arkansas

CALIFORNIA
Stanford University

University of California, Davis Medical Center
- *Partner Site: Kaiser Permanente*

University of California, Irvine

University of California, Los Angeles

University of California, San Diego

University of California, San Francisco

COLORADO
Rocky Mountain Movement Disorders Clinic

University of Colorado

CONNECTICUT
University of Connecticut Health Center

DISTRICT OF COLUMBIA
MedStar Georgetown University Hospital

FLORIDA
University of Florida

University of Miami

University of South Florida
- *Partner Site: Central Florida Center for Huntington's Disease, Winter Park and Orlando, FL*

GEORGIA
Emory University

ILLINOIS
Northwestern University

Rush University Medical Center

INDIANA
Indiana University

IOWA
University of Iowa

KANSAS
University of Kansas Medical Center

KENTUCKY
University of Louisville

LOUISIANNA
Ochsner Health System

MARYLAND
Johns Hopkins University

MASSACHUSETTS
Beth Israel Deaconess Medical Center
- ***Partner Site: University of Massachusetts, Chan School of Medicine***

Massachusetts General Hospital

MICHIGAN
Henry Ford Hospital

MINNESOTA
Hennepin Health Care

MISSISSIPPI
University of Mississippi Medical Center

MISSOURI
Washington University School of Medicine

NEBRASKA
University of Nebraska Medical Center

NEW HAMPSHIRE
Dartmouth Hitchcock Medical Center

NEW JERSEY
Rowan University School of Medicine & Rutgers University RWJ Medical School

NEW YORK
Albany Medical College

Columbia Health Sciences/ NYS Psychiatric Institute

Stony Brook University Hospital

University at Buffalo

University of Rochester

NORTH CAROLINA
Duke University

NORTH DAKOTA
Sanford Health

OHIO
Cleveland Clinic

Ohio State University

University of Cincinnati

OREGON
Oregon Health & Science University

PENNSYLVANIA
University of Pennsylvania
- *Partner Site: St. Luke's University Health Network, Bethlehem, PA*

University of Pittsburgh Medical Center

SOUTH CAROLINA
Medical University of South Carolina

University of South Carolina School of Medicine

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

TEXAS
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*

UTAH
University of Utah

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

VIRGINIA
University of Virginia

Virginia Commonwealth University

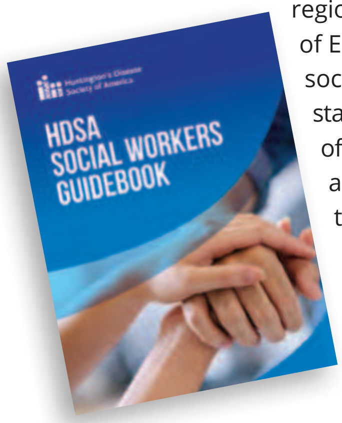
WASHINGTON
University of Washington
- *Partner Site: Selkirk Neurology, Spokane, WA*

WISCONSIN
University of Wisconsin

HDSA Social Workers Network

In 2024, HDSA expanded its network of social workers to 120 nationwide. Thirty-nine of the social workers are community-based and work in conjuction with HDSA local Chapters and Affiliates. Eighty-one social workers are affiliated with HDSA Centers of Excellence clinics. 2024 also saw HDSA's network expand into Montana for the first time, bringing the total of U.S. states served to 45 — Hawaii, Arkansas, Wyoming, West Virgina, and New Mexico being the only exceptions.

HDSA Social Workers Guidebook



The ***HDSA Social Workers Guidebook*** was developed to assist HDSA regional and Centers of Excellence based social workers understand the parameters of their roles, as well as clarify those roles to HDSA Centers of Excellence directors and HDSA Chapter leaders.

Social Worker Orientation

The second **HDSA New Social Worker Orientation** was held in Minnesota, bringing fifteen new HDSA Center of Excellence and HDSA Chapter social workers together to learn from all over the United States.

2024 HDSA Excellence In Care Award

Susan Reynolds, MSW, LCSW, LICSW, was awarded the **2024 HDSA Excellence In Care Award** at the 2024 HDSA Annual Convention in Spokane, WA. Susan is the HDSA social worker for Orange and San Diego counties in California. She facilitates several HDSA support groups in California and an HDSA Washington State Chapter support group.

Free Continuing Education Units

Free Continuing Education Units are now available for all levels of social work expertise. These engaging and informative courses can be found by scanning the accompanying QR Code. New topics covered include:

Course 1: Mental Health Symptoms in Huntington's Disease
Course 2: HD Genetics and the Role of the Social Worker
Course 3: HD In the Family: Implications, Clinical Challenges and Opportunities for Social Work Practice
Course 4: Caregiving for Someone Living with Huntington's Disease
Course 5: Understanding Juvenile Huntington's Disease: Considerations for Social Workers and Other Professionals
Course 6: Understanding the Impacts of HD on Youth & Young Adults
Course 7: Building Resilience and Huntington's Disease
Course 8: Grief and Loss in Huntington's Disease
Course 9: An Introduction to End-of-Life Choices and HD
Course 10: Working Psychologically with Huntington's Disease

BY THE NUMBERS:

HDSA Online Support Groups

IN 2024, HDSA HOSTED

552 online support meetings

ATTENDED BY

1,765 community members

AND RECEIVED A

4.83 star rating from the attendees

★★★★★

Disability Benefits and HD

Disability is often an important part of an individual's Huntington's disease journey. There are many components to the disability process, including: Social Security, private/employer benefits, legal planning, financial planning, health insurance, other insurance, and long-term care planning. Many resources on these Disability Umbrella topics can be found at the Disability Benefits and HD section at hdsa.org/find-help/healthcare-and-future-planning/

With over 110 hours of phone and email communications, HDSA assisted these groups along with other nonprofit individuals with their disability claims, concerns, and/or inquiries:

430 **Individuals**	**60** **Social Workers**	**35** **Lawyers**	**15** **Physicians**

72% of persons with questions concerning disability felt more confident accessing resources and navigating the disability process after reaching out to HDSA. 93% would recommend the HDSA Disability program.

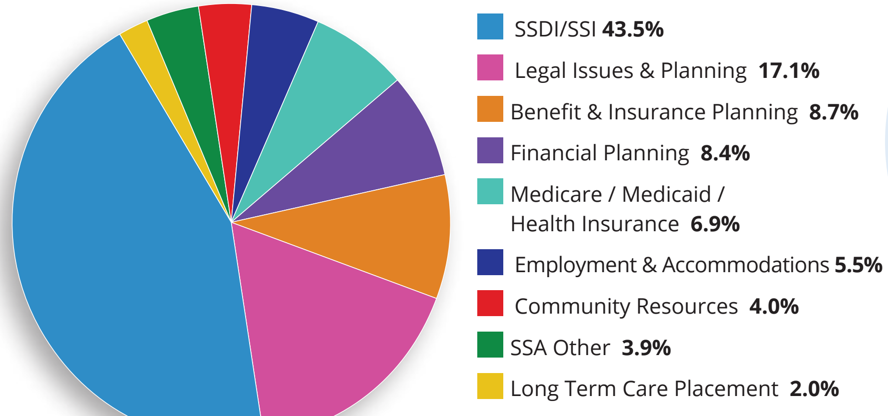
Impactful Communications

In 2024, **HDSA's Disability Benefits & HD web pages had 137,586** views. **135,000** of those views were for the **Disability Tips Blog** posts

Other sections which received the most views included:

- **Webinar/Disability Tip Views**
- **Healthcare Decision Making**
- **Ten Tips for Navigating Social Security Disability**
- **The Disability Umbrella**
- **Discrimination in HD**

Disability Topics Most Asked About



Making a Difference

> *"Great resource. My wife's recent testing revealed Huntington's disease. We did not know where to turn. I read though the Disability program resources, Watched the webinars, did a phone consultation with Allison and finally (and maybe most importantly) she reviewed our application before we submitted it to Social Security."*

Research Round Up

Investing in the Next Generation of HD Scientists

In 2024, HDSA's research programs expanded in scope, reach, and impact; fueling discovery, supporting emerging investigators, and deepening connections between scientists, families, and industry partners. Amid rapid changes in the Huntington's disease (HD) research landscape, we focused on strengthening infrastructure, scaling our most competitive programs, and ensuring patient voices remain central to therapeutic development.

Berman-Topper Family HD Career Development Fellowship

This year marked a significant expansion of the **Berman-Topper Fellowship**. With renewed support from the **Berman** and **Topper** families, the award amount increased from $240,000 to $300,000 over three years, making it one of the most competitive fellowships in HD research. The 2024 application cycle attracted eight proposals from promising early-career scientists. Following rigorous review by HDSA's Scientific Advisory Board (SAB), two Fellowships were awarded:

Dr. Thai Bao Nguyen

Dr. Sonia Vázquez-Sánchez

Dr. Thai Bao Nguyen ***(University of California Irvine, mentored by Dr. Leslie Thompson),*** for his project exploring how the interaction between mutant huntingtin and TDP-43 drives transcriptional dysregulation via m6A-dependent pathways.

Dr. Sonia Vázquez-Sánchez ***(University of California San Diego, mentored by Dr. Don Cleveland),*** for her work using spatial transcriptomics to map toxic molecular events in the HD brain.

Dr. Nguyen began his fellowship on August 1, 2024. Dr. Vázquez-Sánchez began on November 1, supported by a collaboration between HDSA and CHDI Foundation.

In addition to supporting new fellows, 2023 awardee **Dr. Chris Kay** visited HDSA headquarters, participated in Washington Education Day, and co-led a Convention session demystifying CAG repeat expansion in HD — an example of how Berman-Topper Fellowship alumni are becoming public-facing leaders in the field.

Donald A. King Summer Research Fellowship

The Donald King Fellowship saw record participation in 2024, with six summer students selected (the largest cohort in the program's history). Applications were reviewed by a panel of former and current **Berman-Topper Fellows,** reinforcing mentorship across our training pipeline.

Three 2023 Fellows, presented their work at the HDSA Convention in Spokane, WA. Two Fellows also presented posters at the Hereditary Disease Foundation Symposium in Boston, underscoring the growing presence of undergraduates in national Huntington's disease research forums.

2024 Donald A. King Fellowship awardees: Alex De Almeida*, University of Central Florida;* **Ana Ramos De Jesus,** *Columbia University;* **Kaleigh Hanley,** *University of Central Florida;* **Shai Lipkin***, University of Central Florida;* **Abby Matuszak,** *Marquette University;* **Mariana Olivares-Cealy,** *Massachusetts General Hospital*

HD Human Biology Project

2024 saw explosive interest in the **Human Biology Project,** with a record-setting 30 letters of intent and 28 full proposals from 11 countries. Applications spanned a wide spectrum of urgent research priorities: somatic instability, huntingtin clearance, brain circuitry, health disparities, and more.

HDSA's Scientific Advisory Board expanded to accommodate the volume and diversity of submissions, incorporating ad-hoc reviewers from the Broad Institute, Mass General, and CHDI. After thorough deliberation, the following three projects were selected for funding:

Dr. Zachariah McLean *(Mass General):* A novel human cell model to explore how CAG repeat structures and genetic modifiers influence HD onset and progression.

Dr. Dipika Gupta *(NYU Grossman School of Medicine):* Advanced imaging of RNA-DNA hybrid structures that fuel repeat expansion in the huntingtin gene.

Dr. Nicholas Caron *(University of British Columbia):* Multi-omic biomarker discovery using cerebrospinal fluid from premanifest and manifest HD patients.

This year's application and review process leveraged HDSA's new grants management platform, **Proposal-Central,** dramatically streamlining administration and communications.

Dr. Z. McLean

Dr. Dipika Gupta

Dr. Nicholas Caron

Research Round Up

Researcher Spotlight: Dr. Roy Maimon

2023 Human Biology Project recipient, **Dr. Roy Maimon,** is employing a genetic drug which in mice can awaken dormant support cells in the brain and convert them into new neurons. He is now testing this method in human cells. This project will also generate an important map of which genes in which brain areas can best be turned on and off to facilitate a healthier brain network.

Dr. Roy Maimon

Dr. Maimon recently obtained an Assistant Professor position at NYU and is already recruiting collaborators there to bring more researchers into the HD field. About his new position, he offered, "My lab will, of course, be focused on Huntington's Disease, with a mission to induce brain regeneration. Please don't hesitate to reach out if there is any event or initiative you would like me to be involved in. I would be more than happy to support HDSA in any way I can."

> *"The support from HDSA has been truly transformative for both my research and career. As a neuroscientist dedicated to unlocking brain regeneration for neurodegenerative diseases, I have spent years developing an approach to generate new neurons in the aging brain, including in models of Huntington's disease. With HDSA's backing, I have been able to push this work forward - using antisense oligonucleotides to reactivate endogenous stem cells in the brain and applying cutting-edge tools (like Multimodal MERFISH) to map and understand this regeneration process. Their support not only enabled crucial experiments but also helped lay the groundwork for my future independent lab, where I will continue developing therapies that could one day change the lives of HD patients and their families. I'm deeply grateful."*
>
> — DR. ROY MAIMON

HD-COPE (Community Advisory Panel)

In response to evolving partner needs, **HDSA** and the **Huntington Society of Canada** began a full redesign of the **HD-COPE** program to support a more scalable, virtual format. The new model will include modular video training and plans to expand the volunteer base globally. Industry engagements continued:

- **Neurocrine Biosciences** hosted a half-day session in December 2023 focused on chorea.
- **Wave Life Sciences** held a 3-hour advisory board in April.
- **CHDI** hosted two feedback sessions in summer 2024 on the evolving Enroll-HD platform.

Momentum is building for a refreshed and more inclusive HD-COPE in 2025.

Progress in Clinical Trials and Community Participation

As of late 2024, the HD clinical trials landscape remains robust, with over 40 pharmacological and non-pharmacological trials actively enrolling across multiple continents. U.S. participation continues to play a leading role, with at least 25 ongoing interventional trials recruiting or treating participants in the United States, including key studies from **uniQure** *(AMT-130),* **PTC Therapeutics** *(PTC518),* and **Roche** *(GENERATION-HD2).*

Community participation remains strong, likely driven by increased awareness and improved trial navigation tools like **HDSA's Trialfinder.** U.S. families continue to be indispensable contributors to therapeutic advancement, providing not only data but vital insights that shape trial design, implementation, and feasibility.

Looking Ahead

HDSA closed 2024 with new leadership in place — **Tamara Maiuri, PhD** joined HDSA as Associate Director of Research and Patient Engagement. A Huntington's disease researcher and science communicator with deep roots in the HD community, Dr. Maiuri will be leading the 2025 fellowship cycles, driving new outreach efforts, and shepherding **HD-COPE's** relaunch.

As our network grows and the pipeline matures, HDSA remains committed to investing in scientists, amplifying the patient voice, and equipping families with the tools they need to navigate the future of Huntington's disease research.

Dr. Tamara Maiuri, HDSA Associate Director of Research and Patient Engagement

HDSA Education Days

In 2024, the Huntington's Disease Society of America successfully hosted 39 Educational Day Events across 32 states, reinforcing its commitment to providing essential resources, expert information, and community support to individuals and families affected by Huntington's disease. The Education Day Program awarded over $100,000 in grants to HDSA Centers of Excellence, Chapters, and Affiliates in 2024.

Community Outreach

HDSA Education Days are a cornerstone of HDSA's outreach and education efforts, offering attendees access to presentations by leading clinicians, social workers, and researchers. They include discussions on care strategies and opportunities to connect with others in the Huntington's disease community. Each event also incorporates topics from the HD Topic Library, listed below:

- Caregiver and Caregiving 101
- Community Advocacy
- Coping with HD
- Crisis Management in HD
- Crisis Management in HD
- Disease Management Strategies
- End of Life Planning
- Grief and Loss
- HD 101
- HD on the Job: Working while Living with HD
- Importance of Advance Directives
- Intimacy in HD: What Happens When a Person you Love Changes
- JHD 101
- Long Term Care Options
- Mental Health Management
- Navigating Different Stages of HD
- New to HD: Disease Adjustment
- Patient's Right to Self-Determination
- Science and Research Updates
- Self-Care for Caregivers: Beyond Counseling
- Self-Determination and Future Planning
- Social Security Disability
- Stigma and HD
- Therapy 101: Understanding Therapy and Finding a Good Fit

Sponsored Partners

HDSA gratefully acknowledges the active involvement of Genentech, MassMutual Special Care, Neurocrine Biosciences, Teva, and uniQure in HDSA's Education programs. These Sponsored Partners participated in 21 Education events throughout the year. Their presence allowed community members to engage directly with industry professionals, ask questions, and learn about the latest advancements in Huntington's disease research, clinical trials, and support services. Their participation reflects the strength of HDSA's partnerships and its shared commitment to improving the lives of those impacted by Huntington's disease.

HDSA Externally-Led Patient Focused Drug Development Meeting

Overview of HDSA's Externally-Led Patient Focused Drug Development (EL-PFDD) Meeting for People Living with Pre-Symptomatic and Early to Mid-Stage Adult-Onset HD.

On November 13, 2024, 146 people living with Huntington's disease and family members met in person or virtually to share their experience on the impact of living with HD and their perspectives around therapeutics to treat HD with FDA staff and medical product developers. Participants prepared for the meeting by taking the *HDSA HD Symptoms and Treatment Impact Survey.* Additionally, the HD community was invited to share their answers to the discussion questions asked during the meeting through an online portal hosted by HDSA. The meeting was broken into two sessions — the first foocused on health effects and daily impacts of living with HD, while the second dealt with current approaches to treatment.

Health Effects and Daily Impacts

While the comments and the HDSA survey results underscore the diversity in people's experiences living with HD, several key themes emerged:

- The emotional toll of a positive test result
- Living with looming loss of abilities
- Planning for inevitable dependence
- Worries about the future of living with Huntington's disease.

Perspectives On Treatments

Participants shared frustration around knowing that HD symptoms are inevitable, and individuals living with HD and their families are powerless to stop its progression. Further, that despite best efforts to maintain a healthy lifestyle through diet, exercise, and supplements, there is no proven way to prevent or delay the onset of symptoms. While there are medications to treat some of the mental health and movement disorder symptoms, there are no disease modifying therapies that stop the progression.

Preferred Treatment Outcomes

Participants shared that treatment priorities shift depending on the disease stage. In the pre-symptomatic stage, participants emphasized treatments to address subtle changes they are noticing around mental health and cognition. In the early-stage, participants emphasized the importance of addressing cognitive and psychiatric symptoms, such as impaired thinking, memory difficulties, anxiety, and depression. At mid-stage HD, participants shared that treatments that support safe eating, reduce choking risk, and minimize falls were important to them.

Perspectives on Clinical Trials

Participants identified several barriers to clinical trial participation. Stringent eligibility criteria often exclude individuals who do not yet exhibit sufficient symptoms, despite underlying neurodegeneration. Logistical challenges, including travel distance to trial sites and rigid participation requirements, further limit access. Communication issues, such as unclear trial information and technical language, contribute to difficulties in understanding and enrolling.

FDA

HDSA will submit the **Voice of the Patient Report** *to the FDA in 2025. The report will also include the results of the* HDSA HD Symptoms and Treatment Impact Survey. *Once posted on the FDA website, it is available to the public including medical product developers and researchers. When they review the report, the HD community will have told them what their priorities are and what direction they want them to take when conducting research to treat HD.*

TO VIEW THE MEETING AND HEAR TESTIMONIES OF THE PARTICIPANTS' EXPERIENCES WITH HD, SCAN THE QR CODES BELOW:

PART 1:
Health Effects & Daily Impacts

PART 2:
Current Approaches to Trearment

HDSA Marathon Teams

HDSA's Marathon Teams efforts translate into increased awareness, expanded care, and vital research advancements, ultimately strengthening the HD community nationwide. The impact of their hard work and dedication is truly commendable.

2024 Bank of America Chicago Marathon Team HDSA

Congratulations to all the members of the **Chicago Team HDSA** that took part in the **Bank of America Chicago Marathon** from across the U.S. in October. The team of 39 runners, the largest HDSA Chicago Marathon team to date, raised a grand total of **$107,141.** Thank You to Chicago's Team HDSA! Congratulations on a job well done!

2024 TCS New York City Marathon Team HDSA

New York Team HDSA — made up of twenty-seven runners from across the United States — participated in the **TCS New York City Marathon** in November to support the Huntington's Disease Society of America. By race day, the marathon team had raised **$176,700.** Breaking the previous HDSA fund-raising record, set more than 10 years ago, by ten thousand dollars! Congratulations Team HDSA on reaching this new milestone! Thank you!

National Giving Days 2024

National Giving Days encourage people to donate, volunteer, or collaborate to celebrate generosity in support of great causes — like the fight against HD.

RARE DISEASE DAY
February 28, 2024

TOTAL RAISED:
$17,450

FOUNDER'S DAY
September 18, 2024

TOTAL RAISED:
$80,335

GIVING TUESDAY
December 3, 2024

TOTAL RAISED:
$64,746

Huntington's Disease
Society of America

39th Annual HDSA Convention

On May 30th, 2024, HDSA hosted the **39th Annual HDSA Convention** at The Grand Hotel in Spokane, Washington. The event marked the second year there were no-restrictions at an HDSA Convention since 2019 and our first trip back to the west coast since 2018. The Convention welcomed over 770 in-person attendees. All participants were also able to download the free HDSA Convention app which allowed them to connect with other attendees, get updates and much more.

The festivities kicked-off on Thursday with Chapter & Affiliate Leadership Day and Social Worker Professional Training Day, NYA Day, and the Team Hope Walk on the riverfront, alongside the Spokane River, which led to the carnival-themed Welcome Reception. **Teresa Srajer** and **Louise Vetter** delivered the Opening Ceremony remarks and acknowledged **Dr. Thomas Bird, MD** for a lifetime of service to the HD Community. The **Annual HDSA National Youth Alliance (NYA) Talent Show** raised more than $30,000 to support Youth & Young Adult Programs. **HDSA's Research Forum** included researchers and clinicians presenting the latest findings in HD research, and a presentation on **PowerHD** by **Jenne Coler-Dark.** The HDSA Convention came to a close with the **HDSA National Awards Dinner and Gala,** highlighted by the **Candle Lighting Ceremony** dedicated to honoring the HD community.

HDSA Convention Awards Dinner & Gala

2024 HDSA NATIONAL AWARDS

MARJORIE GUTHRIE AWARD
Lisa Hubbard

WOODY GUTHRIE ADVOCACY AWARD
Tracy Toscano

HDSA YOUTH/JHD AWARD
Jenna Woodard

HDSA YOUTH/JHD AWARD
Katie Schroeder

HDSA EXCELLENCE IN CARE AWARD
Susan Reynolds

HDSA PERSON OF THE YEAR
Cathy Harrell

2024 CHAPTER & AFFILIATE AWARD RECIPIENTS

HDSA CHAPTER OF THE YEAR
Missouri Chapter

HDSA AFFILIATE OF THE YEAR
Chesapeake Bay Area Affiliate

OUTSTANDING EDUCATION AND FAMILY SERVICES
Wisconsin Chapter

OUTSTANDING ACHIEVEMENT IN FUNDRAISING
Greater New York Chapter

#LetsTalkAboutHD
Michigan Chapter

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PTC Therapeutics
Vico
Wave

FRIEND SPONSORS
AskBio
Broda
Spark
Stewart Disability Law Firm

1.*The Annual HDSA National Youth Alliance (NYA) Talent Show raised more than $30,000 to support Youth & Young Adult Programs.*

2. *Teresa Srajer and Louise Vetter with HDSA's 2024 Person of the Year, Cathy Harrell*

3. *Teresa Srajer and Louise Vetter presenting HDSA's 2024 Chapter of the Year Award to the HDSA Missouri Chapter.*

4. *Team Hope Walk, HDSA's Annual Convention, Spokane WA.*

5. *Candle Lighting Ceremony honoring those whose lives have been affected by HD.*

HDSA National Youth Alliance

HDSA's National Youth Aliance (NYA) Impact

In 2024, HDSA's National Youth Alliance (NYA) provided in-person opportunities for youth and young adults to connect, learn, and receive support through HDSA's National Convention, NYA's Retreats and young adlt specific support groups. Over 125 individuals and their families were served. Over 60% were first-time attendees to these events and were empowered and inspired to get more involved.

NYA & HDSA's National Convention

HDSA provided 55 scholarships for applicants under the age of 35 to attend HDSA's National Convention in Spokane, WA in May of 2024. The scholarships cover the fees for attending the event. Over 60 young people were in attendance for the Convention's NYA Day — an annual event, held the Thursday prior to the start of Convention each year. The Day is dedicated to NYA members, who come together for education and support. Participants discuss advocacy, fundraising, research and awareness for Huntington's disease. Over $35,000 was raised at the Convention for NYA Programs.

> *"This is my first HD event and it has been the best weekend of my life! No one at home understands and I am so grateful my mom made me come. I am so happy I have a place now."*
>
> — A TEEN ATTENDING HDSA'S 2024 NATIONAL CONVENTION

The Twelve Days of NYA

The Twelve Days of NYA is a fundraising initiative held year-end during the holiday season that directly supports youth programs and scholarships. It is the only NYA fundraiser held outside of the HDSA National Convention. This year, the program raised $8,000.

NYA Retreats

HDSA's NYA hosted two retreats — in Nashville, TN and Phoenix, AZ — in partnership with local HDSA chapters and HDSA Centers of Excellence. The week-end long retreats provided the attendees opportunities to learn, receive support, as well as meet and connect with other young people impacted by HD and Juvenile Huntington's disease. Over 75 young people participated in these events, with travel and hotel accommodations fully funded by the Huntington's Disease Society of America

Youth Social Workers and Support Groups

Over 300 hours of education and support were provided to youth, young adults, parents, and professionals dealing with HD by five HDSA Youth Social Workers. Each month, young adult specific support group sessions were held. Nationally, there are 60 NYA support groups.

To learn more about HDSA's National Youth Alliance, visit NYA/HDSA.org

FINANCIALS

Your HDSA Dollars at Work

OVERVIEW

▲ TOTAL 2024 REVENUE:

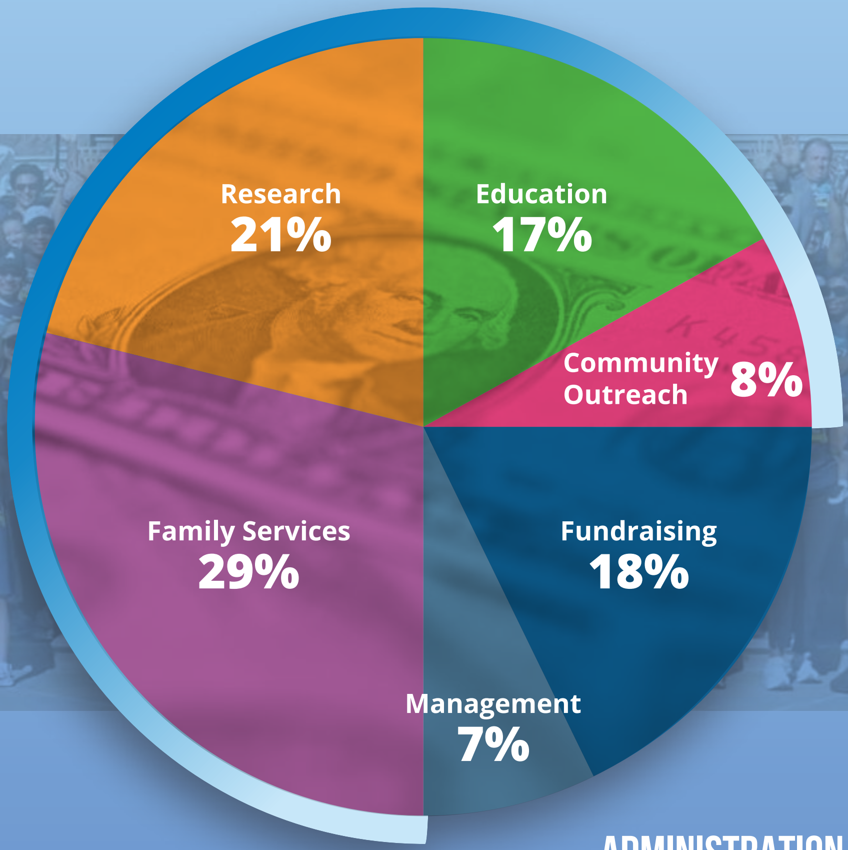
- $11,141,226

▲ FUNDING:

- HDSA Centers of Excellence: $2,091,793
- Research Grants: $1,124,976
- Social Workers: $533,179

▲ FUNDS ALLOCATION:

PROGRAM SERVICES
75%



ADMINISTRATION
25%

MISSION RATIO

75:25

Statments of Financial Position

AS OF DECEMBER 31, 2024 AND 2023

	2024	2023
ASSETS		
Cash and cash equivalents	$7,409,235	$8,552,926
Pledges and contributions receivable, net	1,567,241	952,490
Investments	5,503,140	5,742,903
Prepaid expenses and deposits	251,907	377,139
Right-of-use asset	2,425,693	2,646,072
Property and equipment, net	162,905	191,288
Website and software costs, net	545,761	574,969
Total Assets	**17,865,882**	**19,037,787**
LIABILITIES		
Accounts payable and accrued expenses	139,416	206,181
Accrued compensation	262,658	267,435
Grants payable, net	1,747,581	1,152,674
Event revenue received in advance	22,336	32,349
Lease liability	2,463,171	2,649,001
Total Liabilities	**4,635,162**	**4,307,640**
NET ASSETS		
Without donor restrictions		
Undesignated	6,337,546	7,428,178
Board-operating reserve	3,440,366	3,281,277
Total net assets without donor restrictions	9,777,912	10,709,455
With donor restrictions		
Purpose restrictions	2,925,306	3,710,692
Time-restricted for future periods	277,502	60,000
Perpetual in nature	250,000	250,000
Total net assets with donor restrictions	3,452,808	4,020,692
Total Net Assets	**13,230,720**	**14,730,147**
Total Liabilities And Net Assets	**17,865,882**	**19,037,787**

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, 2024 WITH SUMMARIZED FINANCIAL INFORMATION FOR 2023

	2024	2023
SUPPORT & REVENUE		
Public donations	3,896,244	3,577,191
Foundation grants and corporate contributions	2,349,082	2,596,531
Federated campaign	179,272	238,917
Special events (net of direct benefit to donors of $514,170 and $553,989 in 2023 and 2022, respectively)	3,711,403	3,676,186
Investment earnings, net	198,735	162,979
Donated services and materials	205,833	183,645
Other income	32,773	59,035
Total support and revenue before net assets released from restrictions	10,573,342	10,494,484
Net assets released from restrictions	——	——
Total Support and Revenue	**10,573,342**	**10,494,484**
EXPENSES		
Program Services:		
Research	2,499,991	2,707,522
Family services	3,581,972	3,639,573
Education	2,036,134	2,011,739
Community outreach	938,029	966,340
Total program services	9,056,126	9,325,174
Supporting Services:		
Management and general	902,916	691,758
Fundraising	2,227,384	1,867,085
Total supporting services	3,130,300	2,558,843
Total Expenses	**12,186,426**	**11,884,017**
Change in net assets before previous year rescinded grant, returned grant funds, and gain on lease modification:	(1,613,084)	(1,389,533)
Previous year rescinded grant	——	140,000
Returned grant funds	113,657	79,141
Gain on lease modification	——	60,921
Change in net assets	(1,499,427)	(1,109,471)
Net assets - beginning of year	14,730,147	15,839,618
Net Assets - End of Year	**13,230,720**	**14,730,147**

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.*

SPECIAL THANKS

We are grateful for the gifts from the following estates who helped make our work possible in 2024.

Bequest of Florence B. Cofone

Bequest of Francis Nolan

Bequest of Nancy Burnett

Bequest of Philip Sykes

Estate & Trust Administration of Jean A. Meyer

Estate of Barbara L. Bell

Estate of David Guggenheim

Estate of Dean Gleckler

Estate of Jeffery D. Hill

Estate of John Nargi

Estate of Marilyn Polinger

Hazel Hitt Endowment of the Community Foundation of West Texas

Jane G. Clark Trust Agreement

Janice L. White

John E. Goerlich Charitable Trust

LeRoy R. Clark Trust

Nancy F. Rheingrover

The Estate of Jill Dean

The Estate of Susan J. Pfeiffer

The Raye Michelle Phillips Irrevocable Trust

United Life Insurance Company

Huntington's Disease
Society of America

The Marjorie Guthrie Society

In 1967, Marjorie Guthrie launched an all-out assault on the disease that would soon claim her husband, Woody Guthrie. Her efforts led to the founding of the Huntington's Disease Society of America. Throughout her life she remained a powerful voice in the fight against HD.

CREATE A LEGACY OF GIVING THAT GUARANTEES VITAL SUPPORT FOR FUTURE GENERATIONS

Until the day when scientists find a cure for HD, families across the country require access to vital research, care, disability, advocacy, and education programs and more that 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 plan 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.

Haven't made your plans yet?

No problem, we've partnered with FreeWill to help you write your will for free! This secure online resource helps you complete your will in 20 minutes from the comfort of your home. Even if you have a complex estate or prefer to finalize your will with an attorney, this tool can also be used to create a list of documented wishes, saving you time and money. To learn more about the Marjorie Guthrie Society, or to inform us of your estate plans to support HDSA, please contact our National Development team at natdev@hdsa.org or visit us online at **www.hdsa.org/get-involved/planned-giving.**

Thank you to the following who have committed to support HDSA through their estate plans:

Anonymous (57)

Norman Baldwin

Nancy & David Clarke

Catherine Hayes
& Mark Wiesel

Dr. Barbara Heere

Amy Korber

Daniel & Katy Leonard

Jessica Marsolek

Matthew Marsolek

James Norris

Lachelle Parker

Mark Pinto

Gordon Sparks

Craig & Teresa Srajer

SAVE THE DATES!

Huntington's Disease Society of America

HDSA 41ST ANNUAL CONVENTION

PHOENIX ARIZONA

JUNE 25-27, 2026

Huntington's Disease
Society of America

505 Eighth Avenue
Suite 1402
New York, NY 10018
(212) 242-1968
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
- **Disability Services:** HDSA.org/disability
- **Clinical Trial Participation:** HDtrialfinder.org
- **Locate Resources Near You:** HDSA.org/locateresources
- **Youth & Young Adult Services:** nya.HDSA.org

MISSION

To Improve the Lives of Everyone Affected by Huntington's Disease and Their Families.

VISION

A World Free of Huntington's Disease.

Highest Ratings

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

CARE

RESEARCH

COMMUNITY