

2024 Help 4 HD International Annual Report

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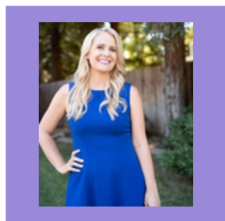
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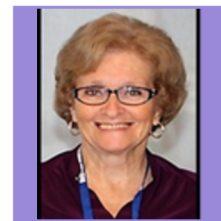
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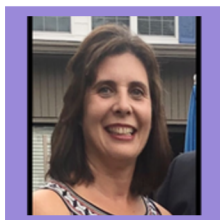
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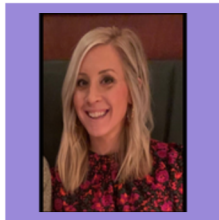
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About Help 4 HD International

Help 4 HD International Inc. began in 2011 as a radio show. Founded by Melissa Biliardi as part of a promise to her son to do everything in her power to fight Huntington's disease, the grassroots effort has grown exponentially over the past ten years. Incorporated and tax exempt in 2013, Help 4 HD's mission is to educate the world about Huntington's disease (HD) and Juvenile Huntington's disease (JHD) through its multimedia communications platform. Through live events, HIPE, Help 4 HD Radio, Help 4 HD TV, symposia, Help 4 HD support groups, HD Awareness Month Campaigns, The Huntington's Post, conferences, publications, Database, law enforcement education, first responder education, and the HD Family Relief Fund, Help 4 HD brings education, information, and resources to the global community, partnering with medical professionals, researchers, institutions and industry for the most current and credible information and resources available. Help 4 HD's goal is to continue establishing solid roots in

underserved communities and to seek out new, underserved areas to educate, help, and serve. Help 4 HD envisions a world where everyone knows what Huntington's disease and Juvenile Huntington's disease are, a world in which compassion is a normal response to the devastation that this horrific disease bestows on everyone. This can only be accomplished through positive education and advocacy efforts. All of Help 4 HD's amazing staff and volunteers have the same desire to help and serve. Each has a strong connection to HD and JHD and understands the burdens that all HD families face. Help 4 HD is committed to its caregiver support and education initiatives, providing information about research and clinical trials. Connecting credible care professionals with the community is a top priority.

Letter from the President/CEO

To Our Incredible Huntington's Disease Community, Partners, and Supporters,

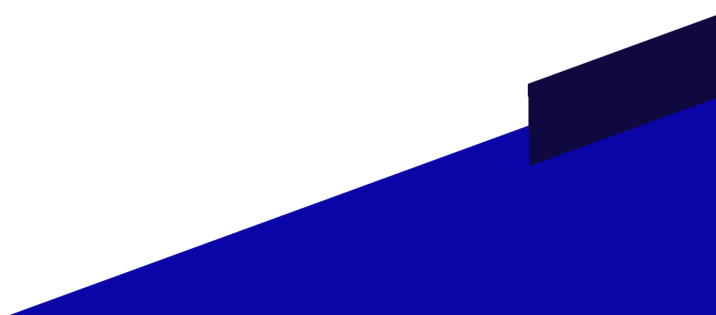
As President and CEO of Help 4 HD International, I am profoundly honored to share the successes and milestones of the past year, detailed in this 2024 Annual Report. Our work is driven by the resilience and hope of the Huntington's disease (HD) community, and our programs are designed to meet the emotional, physical, and financial challenges you face daily.

In 2024, our commitment to providing education, support, and resources reached thousands, breaking down isolation and bringing vital information right into homes across the nation.

Highlighting Our Impact in 2024

Our **Highly Interactive Participant Education (HIPE)** program demonstrated a powerful blend of in-person connection and virtual reach. We hosted four Help 4 HD Education Days , including successful in-person events in Houston, TX (with 174 in-person and 1,961 virtual attendees) and Chicago, IL (with 114 in-person and 1,749 virtual learners). Our evening social events at HIPE and the Annual Symposium in Arlington, VA, created essential safe spaces where families could feel loved, supported, and free from public judgment. Additionally, our two virtual HIPE days continued to be a critical resource, reaching a combined total of over 4,290 virtual attendees.

The dedication to virtual support was further solidified through our digital platforms:

- **Help 4 HD Live!**, our longest-running program, continued to broadcast weekly with over 600 archived episodes available for the community.
 - **Help 4 HD TV** now has over 250 episodes on YouTube and Facebook, allowing us to break down complex conference content into more manageable segments.
 - Our social media outreach remains at the forefront of our communication, reaching different generations and receiving around **150,000 impressions and engagements every 28 days**.
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Expanding Support and Advocacy

We are especially proud of the growth and launch of new initiatives focused on comprehensive support:

- **Support Groups:** We significantly expanded our virtual support groups to include a **Spanish-speaking** group, a **JHD support group**, a **PPEM group** for those pre-symptomatic or in early stages, and the general "**Monday Mixer**".
- **Social Work Program:** A major addition in 2024 was the launch of our Social Work Program, designed to empower community members by connecting them with formal and informal support systems, including Resource Linkage, Advocacy, and connection to HD Expert Care Providers. This program is essential for helping our community develop resiliency.
- **Financial Relief:** We provided tangible relief through our funds. The **Huntington's Disease Family Relief Fund** distributed **\$71,767** to assist with emergency costs, quality-of-life bills, and holiday assistance. Furthermore, our **Genetic Testing Relief Fund** provided over **\$41,775** in testing cost relief to eliminate financial barriers to this crucial step.
- **Education and Awareness:** We exhibited and presented at national and international law enforcement meetings through our LEEP program, educating over 1,100 Crisis Intervention Teams agents and over 1,000 co-respondents about HD. Our May HD Awareness Month campaign saw **76,819 video views** across social media.

As we look ahead, we remain focused on the belief that for all the things our community members have no control over, we can empower them by helping them regain control over the things they can. Thank you to our dedicated sponsors—Teva Pharmaceuticals, Neurocrine Biosciences, and the Griffin Foundation, among many others—for their invaluable support in making every program possible.

With gratitude and hope,

Katie Jackson
President/CEO, Help 4 HD International



2024 Annual Report Notes

Programs

Highly Interactive Participant Education (HIPE)

In 2024, Help 4 HD International (H4HDI) hosted **four Help 4 HD Education Days**. These events are one-day conferences for the Huntington's disease (HD) community to come and hear keynote speakers speak on clinical trials, care, science, and services.

HIPE Houston, TX

- **Speakers and Attendance:** Help 4 HD welcomed **23 speakers**. We had **174 HD family members** show up in person and **1,961 virtual attendees**.
- **Format:** The event hosted two rooms of education and a room dedicated to childcare so families could concentrate on the content.
- **Sessions Included:** HIPE Expert Q and A panel, adaptive equipment, patient perspective panels, guilt and grief, and research updates.
- **Evening Event:** An evening event was hosted filled with music, dancing, great food and beverages, providing a fun, worry-free, and supportive environment for the community.

HIPE Chicago, IL

- **Speakers and Attendance:** Help 4 HD International welcomed **15 speakers**. We had 114 HD family members in person and **1,749 virtual learners**.
- **Sessions Included:** The power of patient advocacy, personalized medication care based on DNA, our expert Q and A HIPE panel, and research updates.
- **Evening Reception:** An evening reception was hosted with music, a photobooth, food, beverages, and community support.



Virtual HIPE Days

All HIPE days had to go virtual during the pandemic, which gave the community unable to leave their homes an opportunity to participate. The response has been so positive that Help 4 HD has decided to hold two virtual HIPE days next year in between the in-person events.

- **Virtual Event Features:**

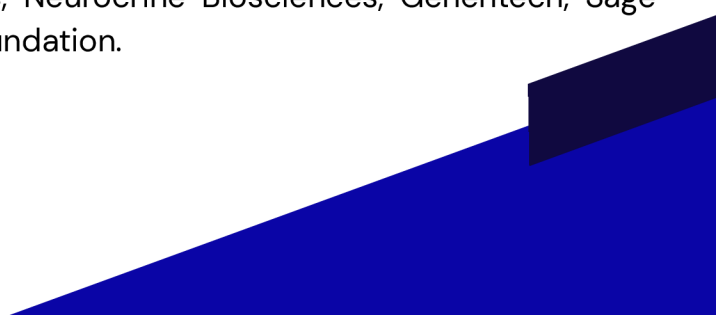
- Hundreds of **Swag Giveaway Registration Boxes** were sent out, full of Help 4 HD swag and resources from sponsors.
- Families participated in event session random giveaways.
- The conference was offered on many different live-stream platforms to ensure participation.
- Community members could pre-submit questions for speakers, an opportunity usually reserved for in-person attendees when events are streamed.

In 2024, Help 4 HD hosted two virtual HIPE days:

- **First Virtual HIPE:** Took place on **February 24, 2024**, with the theme "Lonely BUT Not Alone".
 - **Attendance:** 1,890 people tuned in virtually.
 - **Speakers & Topics:** Welcomed 18 speakers covering topics like intimacy, how love changes with HD, loving yourself, feeding tubes, sacrifice, understanding chorea, the HD HIPE Expert Q and A panel, and research updates.
 - **Swag Boxes:** 300 "Help 4 HD Swag boxes" were sent nationwide.
- **Second Virtual HIPE:** Held on **July 13, 2024**, with the theme "**The Experts**". The goal was to highlight that while there are medical professionals, the true HD experts are the families living it every day.
 - **Attendance:** Over 2,400 people tuned in virtually.
 - **Speakers & Topics:** Welcomed 12 speakers. Sessions included a Q and A with long-time HD caregivers, the HD Expert HIPE panel, breaking news, and research updates.
 - **Swag Boxes:** 250 HD registration swag boxes were sent nationwide.

HIPE Metrics: In 2024, HIPE social impressions reached **63,010**.

Thank You to HIPE Sponsors: Teva Pharmaceuticals, Neurocrine Biosciences, Genentech, Sage Therapeutics, uniQure, Prilenia, PTC, and the Griffin Foundation.



Help 4 HD International Annual Symposium

Help 4 HD International hosted its annual symposium in 2024 in **Arlington, VA**.

- **Attendance:**
 - **34 speakers** were welcomed.
 - **243 people** attended in person.
 - **1,700 people** attended virtually on Friday.
 - **1,200 people** attended virtually on Saturday.
- **Evening Events:** Two evening events were hosted with music, food, beverages, photo booths, community, and fun. This part of the symposium is crucial as it takes families out of isolation and gives them a safe, supportive place where they feel loved and can have a fun night.
- **Exhibitors:** **21 exhibitors** that support the HD community were hosted.

Thank You to Symposium Sponsors: Teva Pharmaceuticals, Neurocrine Biosciences, Sage Therapeutics, Genentech, Wave Lifesciences, Prilenia, uniQure, PTC, and Spark Therapeutics.

Help 4 HD International Support Groups

Help 4 HD International launched its first virtual support group in 2020 during the pandemic, and this **caregiver group** still meets every Tuesday at 5:00 PM ET.

In 2024, several new support groups were introduced:

- **Spanish-speaking support group.**
- **JHD (Juvenile Huntington's Disease) support group.**
- **PPEM support group** for individuals who are at risk, gene-positive, pre-symptomatic, or in the early stages of HD.
- **"Monday Mixer,"** a group that does not target any specific subpopulation and provides a safe space for anyone affected by HD to share experiences and receive peer support.



Help 4 HD TV

Help 4 HD TV emerged from the pandemic as a **weekly show that runs on YouTube**. All filming is done on Zoom, edited, and runs every Friday.

- **Content:** The show covers topics like care, support, resources, Q and A, MythBusters, and much more.
- **HIPE Breakdown:** The platform is used to break down HIPE day's questions into five-minute or so episodes, which is more retainable for the community than a four-hour conference.
- **Metrics:** The show has over **250 episodes available** on YouTube and Facebook.

Shows that ran in 2024 on Help 4 HD TV included:

- Seizures and JHD
- Demystifying HD research
- Help 4 the Holidays
- Medication Management
- Research updates
- Actionable things to do Late, Mid, and Early stage HD
- Sleep issues/Hallucinations and sleep in HD
- Apathy is it cognitive or psychiatric
- Understanding CAG
- HD and Gut Issues
- Medications for Outbursts
- Are you Aware campaign
- HD Database
- "There is no way to know what the end of the HD journey will be like"
- Love is support
- 4 part series of Research Conversations

Thank You to Help 4 HD TV Sponsors: Teva Pharmaceuticals and the Griffin Foundation.



Help 4 HD Live!

Help 4 HD Live! is the program that **launched Help 4 HD International back in 2010**. It was started from a kitchen table using BlogTalk Radio (BTR) to bring **education and resources** to the community virtually.

- **Reach:** The show grew to an international listenership, with over **200,000** all-time listenership since the beginning.
- **Availability:** All radio shows are archived and available on iTunes, iHeart Radio, Spotify, and BTR. There are over **600 archived episodes**.
- **Content:** Topics covered include research, care, resources, regulatory, patient advocacy, inspiration, and more. It informs patients and caregivers about symptoms, symptom management, clinical trials, research, and resources.
- **Schedule:** "Help 4 HD Live!" goes live **every week on Thursday at 1:00 pm PT** and runs for about an hour.

Some shows **hosted on Help 4 HD Live in 2024** included:

- HD Resources Review
- Book Reviews like Bloopy the Alien
- Research Updates
- Rare Patient Voices
- HD RSC
- Update on Partnering Organizations
- HD Uncut
- Gratitude Day
- HD Charge
- Livable Lives
- Social Work Segments
- Coping During the Holidays

Thank You to Help 4 HD Live Sponsors: Teva Pharmaceuticals, Neurocrine Biosciences, and the Griffin Foundation.



Help 4 HD Law Enforcement and First Responders Education Program (LEEP)

Help 4 HD International continued to send its law **enforcement toolkit** to families for free across the nation. The toolkits include car decals and "I Have HD" wallet cards.

- **Conferences:** Help 4 HD attended three national and international law enforcement meetings.
- **CIT International Conference** (Indiana): Exhibited and presented, educating over **1,100 Crisis Intervention Teams** agents through one-on-one conversations and a one-hour presentation.
- **Co Responders International (Omaha, Nebraska):** Exhibited and presented, coming into contact with over **1,000 co-respondents** to talk about HD.
- **Mobile App:** We have a mobile app that has access to all of our free educational content for law enforcement trainers and an easy request process for direct support.

Thank You to LEEP Sponsors: Teva Pharmaceuticals, uniQure, and the Griffin Foundation.

Help 4 HD International Publication

The publication program offers all materials free to the community and professionals.

Brochures and Publications Included:

- "What is HD?"
- "Who is Help 4 HD?"
- "Safe Proofing Your House"
- "Participating in a Clinical Trial"
- "Help 4 HD Care and Resource Binder"
- "HD Cookbooks"
- "Life Interrupted 1 and 2"
- "31 Days of HD, I Fight For..."
- "What I have Learned Being a Caregiver"

Thanks to Teva Pharmaceuticals and the Griffin Foundation, publications were **free at all in-person events** and included in the **HIPE Virtual registration HD Swag Boxes**.



Huntington's Disease Family Relief Fund

This fund was created to help HD/JHD families with emergency costs they are unable to pay.

- **Assistance Provided:**
 - Comfort devices like weighted or cooling blankets.
 - Household quality-of-life bills and essentials.
 - Emergency assistance, including help through natural disasters.
- **Holiday Assistance Program:** This program helps families with meals brought into their homes around the holiday season, as HD families often cannot afford anything extra.
- **Total Relief:** Help 4 HD International helped with **\$71,767 in funds to HD families** that needed relief.

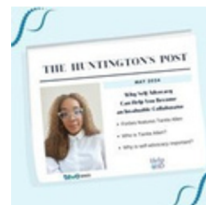
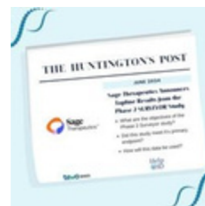
The Huntington's Post

The Huntington's Post is an online newspaper that brings informative reporting to the HD community.

- **Topics Covered:** Clinical trials, event reports, genetic testing, caregiver support, guilt, grief, resilience, press releases, family planning, psychiatric symptoms, cognitive symptoms, chorea, law enforcement, public impact, and many other topics.
- **Community Contributions:** The Post is open for community members to write, and submissions of poems, personal stories, and other topics have been published.
- **Metrics (2024):**
 - **35 articles** were posted.
 - Over **8,720 reads**.
 - Over **55,000 social media impressions**.

Some Help 4 HD Post Articles Included:

- When Hope Expires
- Myth or Fact
- Research updates
- Navigating outbursts
- Clinical trial overviews and updates
- CAG variabilities
- Patient stories
- Awareness campaigns



May is HD Awareness Month Project

In 2024, Help 4 HD ran a **31-day social media campaign**. An awareness video created by the community was posted every day.

Campaign Themes Included:

- **Unmasking the Truth:** Raising awareness about misconceptions and myths.
- **United Against HD:** Emphasizing unity and solidarity.
- **Breaking the Silence:** Seeking to break the stigma and encourage sharing stories.
- **Hope in the Face of HD:** Focusing on resilience and hope.
- **Know the Signs, Know the Facts:** Educating people about early signs, symptoms, research, and treatment options.
- **Love Knows No Bounds:** Highlighting unconditional love and support.
- **Be a Voice for HD:** Encouraging advocacy.
- **Invisible No More:** Raising awareness about the invisible nature of the disease.
- **Breaking the Cycle:** Focusing on early detection, diagnosis, and treatment.
- **Empowered to Care:** Empowering caregivers and professionals to support those affected.

Campaign Metrics: The campaign received **76,819 video views** across social media. Additionally, **300 boxes** were sent nationwide to families with awareness materials like a beanie, shirt, awareness bracelets, and car flags.

HD Resource Database

Launched in 2023, this is an **interactive database** where families can post resources that have helped them and submit requests for assistance like housing, food, respite, and mental health resources.

2024 Database Metrics: The database had **52 locations**, **70 categories**, and **25 support organizations**.

Thank You to Database Sponsors: Teva Pharmaceuticals, Neurocrine Biosciences, and the Griffin Foundation.



Help 4 HD Social Media

Help 4 HD International started in 2010 as a virtual company with the goal of using new-age technology and social media to find as many Huntington's disease families as possible, particularly the large amount of the community that was not going to HD specialty care.

- **Platforms:** The community is reached through Facebook, private and public Facebook groups administered by H4HDI, Instagram, Twitter (X), and TikTok. Different platforms reach different generations (e.g., young people on TikTok, older generations on Facebook).
- **Posting Frequency:** Posts are made on Facebook every single day, and on TikTok, X (formally Twitter), and Instagram multiple times a week.
- **Metrics:** On average, the organization receives around **150,000 impressions and engagements every 28 days.**

Help 4 HD International Genetic Testing Relief Fund

This fund aims to remove the financial cost of the testing process as a barrier for individuals who decide to undergo genetic testing.

- **Total Relief:** In 2024, Help 4 HD helped with over **\$41,775 in testing cost relief** to the HD community.



Social Work Program

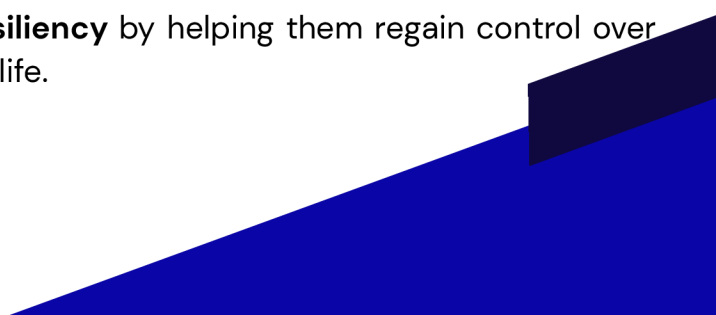
In 2024, Help 4 HD International launched a Social Work Program for the HD community. The program is designed to empower community members by connecting them with resources that will strengthen both informal and formal support systems, aiming to reduce burdens and feelings of isolation.

- **Linkage:** Community members can be linked with a social worker through the database, social media requests, and the Help 4 HD website.
- **Areas of Focus:**
 - Resource Link
 - Advocacy
 - Linkage to Peer Support
 - Linkage HD Expert Care Providers and Clinical Trial sites
 - Linkage to Educational Resources and Events

Examples of Social Work Services Include (provided by social workers Jamie and Anna):

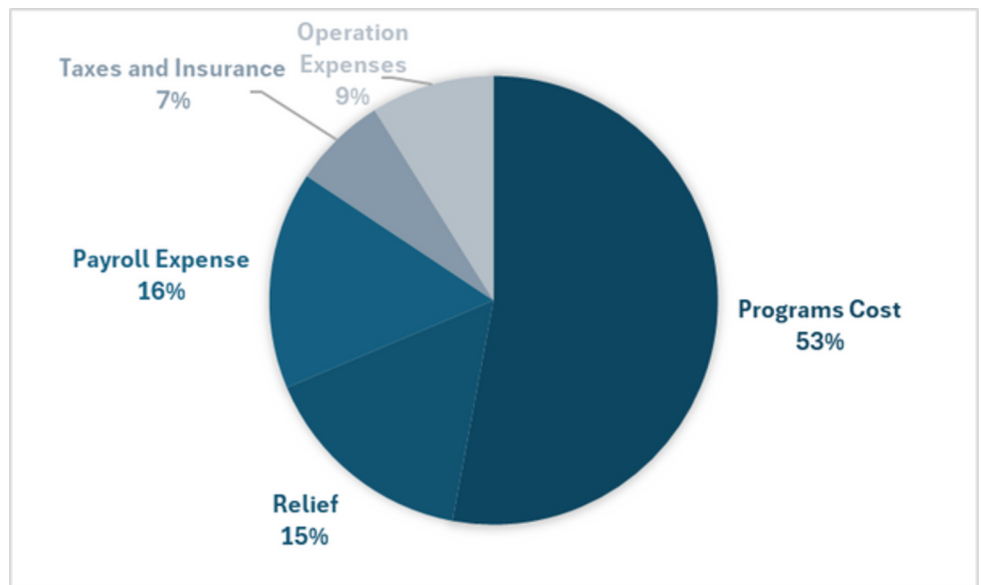
- **Resource Link:** Provided resources to assist clients in overcoming barriers, such as resources for Federal Health Insurance Programs (Medicaid, Medicare, SSDI/SSI), Federal and State Caregiver Programs, resources from other HD Non-Profits, mental health providers, HD-specialized medical providers, and local community service programs.
- **Clinical Trial and Care:** Helped families seeking involvement in clinical trials or having trouble finding care resources by connecting them with the closest HD expert care providers and clinical trial sites in their area.
- **Advocacy:** Provided community members with various platforms for self-advocacy both inside and outside of Help 4 HD. The social worker will also advocate for systematic change if provided an opportunity on mezzo or macro level.
- **Linkage to Peer Support:** Assisted community members with linkage to peer support through support groups and accessible HD-specific community events, and helped facilitate Help 4 HD's Virtual/In-Person Support Groups.
- **Linkage to Educational Resources/Events:** Contacted clients requesting room scholarships to HIPE/Symposium to establish a professional relationship and assess barriers beyond the initial reason for engagement.

The program helps community members develop **Resiliency** by helping them regain control over the things they can, which is essential for a qualitative life.



Financial Impact

Category	Amount
Programs Cost	\$382,901.29
Relief	\$113,574.75
Payroll Expense	\$113,574.75
Taxes and Insurance	\$48,917.47
Operation Expenses	\$64,303.12



Income Amount

