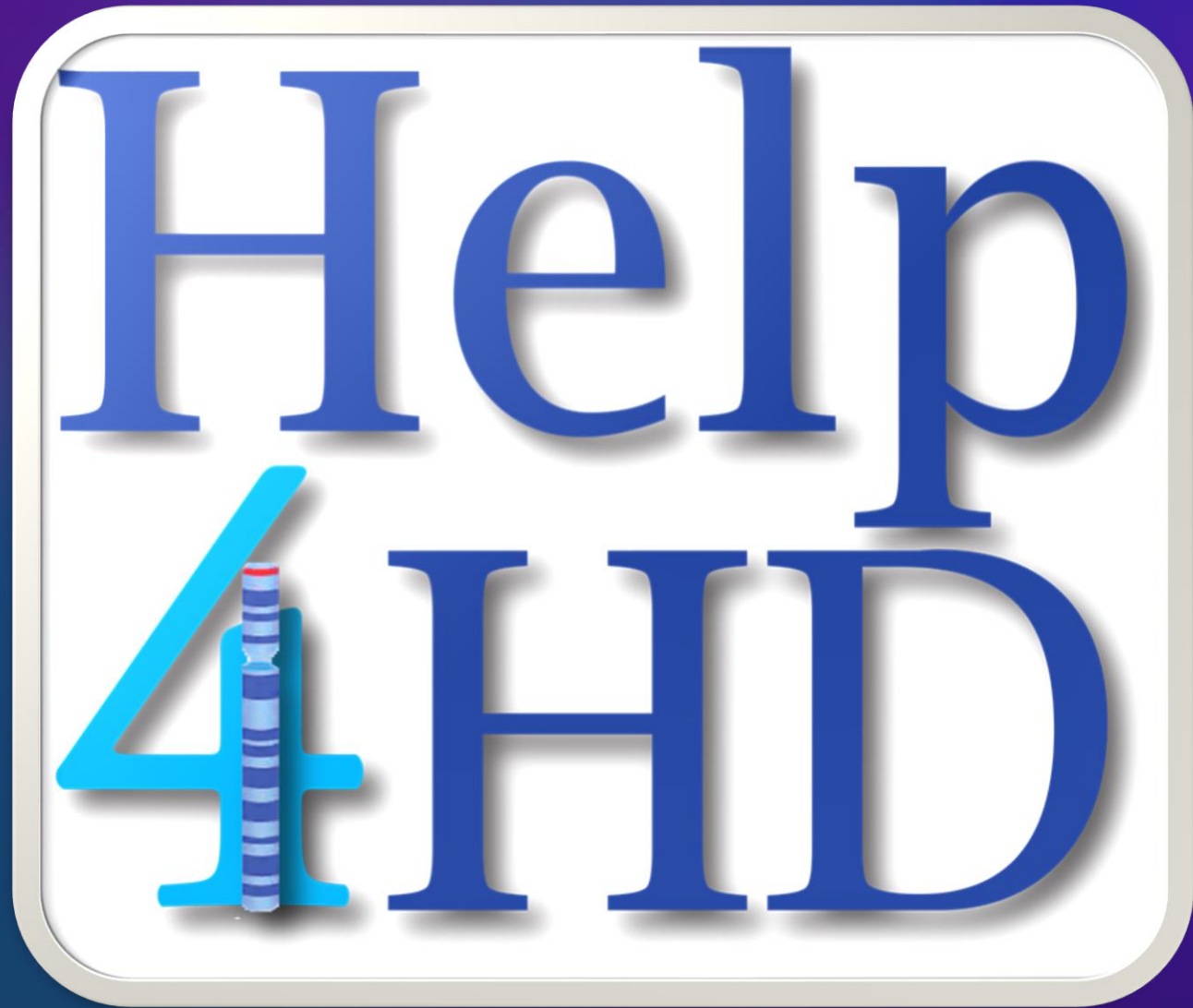


# A LOOK BACK ON 2023

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HELP 4 HD INTERNATIONAL'S 2023 ANNUAL REPORT

[WWW.Help4HD.org](http://WWW.Help4HD.org)



# *Message from the President*

## Part 1

Everyone at Help 4 HD International is working hard every day to educate the world about Huntington's disease. As a company, we are identifying unmet needs within the community and building programs to help fill some of the gaps. We hold tight to our grassroots and use our experiences living in families impacted by Huntington's disease to develop and implement programs we believe will truly assist our community in navigating their very difficult journey living with Huntington's disease.

Help 4 HD International hosts the very first radio show created for the Huntington's disease community. We will continue bringing important, credible information to the Huntington's and Juvenile Huntington's disease communities in the comfort of their own homes. We wrapped up 2023 having aired our 596th episode. We are thankful to have Lauren Holder on our team, providing our community with valuable information, resources, and education through this program. We remain the first ever, longest running, and only weekly podcast focused on the Huntington's disease community.

Another weekly Help 4 HD International program is Help 4 HD TV. We closed this year having aired 239 episodes covering a wide range of topics including HD resources, caregiver burnout, benefits and insurance, cognitive issues in HD, talking about HD with children and the public, advocacy, safe eating, dating, awareness campaigns, research updates, loneliness, living with chorea, psychiatric symptom management, crisis intervention, feeding tubes, and message banking.

This year, Help 4 HD International attended and exhibited at three law enforcement meetings in North Carolina, California, and Michigan. In North Carolina we exhibited at the Chief of Police Annual Conference and Expo. In Michigan we not only exhibited but were also selected to teach a session at the Crisis Intervention Teams International Annual Conference, meeting 1,100 first responders, co-responders and crisis intervention team members from across the nation. We continue visiting local law enforcement mental health agencies and advanced officer training courses to aid officers and first responders in better understanding Huntington's disease. We persist in distributing our Huntington's Disease Law Enforcement Education materials nationally. We also continue offering window decals labeled "Someone with Huntington's Disease is Onboard" and HD ID cards at no cost, which hundreds utilize annually.

In 2023, Help 4 HD International assisted many Huntington's and Juvenile Huntington's disease families in need through our Family Relief Fund, which we firmly believe provides vital support. We understand Huntington's disease brings financial devastation to many impacted families. Our relief fund has helped supply food, clothes, quality of life essentials, utility payment assistance, gas cards, travel expenses to appointments and more. We also provided meal cards for holiday meals and operated a toy drive for children living in homes impacted by HD.

In 2023, we ran our HIPE (Highly Interactive Participant Education) program. Help 4 HD conceived this interactive program in response to needs within the HD community. Collectively caregivers, patients and medical professionals discussed real life scenarios and suggested strategies for dealing with issues families face. We sorely missed convening in person during the pandemic. This year we assembled in Detroit and Puerto Rico, while recognizing the ongoing value of virtual access through two online HIPE days. We also shipped hundreds of HD Swag boxes containing wearables, awareness bracelets, first aid kits and HD information and resources. Registration for these complimentary virtual events and swag boxes typically fills within days.

We capped off 2023 hosting our annual symposium in San Diego with speakers from across the nation providing research updates and guidance on navigating HD journeys. While the talks proved worthwhile, the true magic occurred during both evening social gatherings. We came together, sharing laughter, tears and dance as a community there for one another.

We look forward to growing partnerships with other organizations. This year we teamed with HD Genetics to fund testing costs for families and with the Hereditary Disease Foundation to feature young scientists on Help 4 HD Live! who are unlocking HD mysteries to pave the way for future treatments and a cure.



We continue operating our weekly caregiver support group and bimonthly JHD group, with plans to introduce additional virtual support in 2024.

Our most exciting 2023 launch was the Help 4 HD Resource Database, harnessing AI with human vetting to consolidate helpful resources in one place. We also hired a social worker to assist community members.

We strive at Help 4 HD International to prevent future generations from suffering Huntington's disease as we and previous generations have. Our dream is to transform unawareness into awareness and lack of compassion into empathy. We work through education to make this dream a reality. We remain in the trenches alongside our community, wholly committed to supporting those impacted by Huntington's disease and educating the world about the many challenges they face.

—Katie Jackson



*2023 Help 4 HD Board of Directors*

# *2023 Help 4 HD International Programs*

1. Family Relief Fund
2. HD Resource Database
3. Help 4 HD Live!
4. Help 4 HD TV
5. HIPE (Highly Interactive Participant Education)
6. LEEP (Law Enforcement Education Program)
7. Help 4 HD Support Groups
8. Help 4 HD Awareness Month Campaign
9. The Huntington's Post
10. Help 4 HD Symposium



# Help 4 HD Family Relief Program

## Community Comments:

- I have 3 children plus my self I have Huntingtons disease and can't afford clothing for winter for myself or children I'm asking help for clothes to keep warm.*
- My baby is in need of diapers and I do need essentials as of right now so thank you so much.*
- I have an eviction notice pending and this is going to help me tremendously. You have no idea how grateful I am right now.*
- I was fired due to missing days and weeks of work because of my depression from HD and I am struggling to pay my rent because disability is taking a while.*
- I was unfortunately diagnosed with HD a year and half ago. I am the youngest of 4 siblings. And I have a 5 year old son. I'm unable to work to help my girlfriend pay the bills and with the cost of everything going higher it's hard to just get by sometimes.*
- You have no idea how incredibly thankful I am to you for all your help and time and everyone else to make this possible. I've been in panic mode each day closer to Christmas now its like a weight was just lifted on my shoulders. Honestly words can't describe how much I appreciate it all!*

Help 4 HD International helped hundreds of families nationwide. This year, Help 4 HD International spent \$55,166 to help people with genetic testing, food, clothes, energy, medical expenses, quality of life/hygiene essentials, and more. We are proud to have this program to help our HD community, which often is in desperate need of something as simple as quality-of-life essentials. We want to thank Neurocrine Biosciences, Resortica, Griffin Foundation, the Harmon/Miller family, the Jennings family, the Snider family, all the Facebook fundraisers, the memorial fund, and all who donated through the website to make this significant program possible.

Thank You Sponsors:





## Community Comments :

- This is important; thank you for all you do for the community.
- Lots of hard work went into this! It will help so many people
- So excited to see what I can find in this amazing database!
- This database is full of information. There are things I found that I didn't know existed to help people living with a disease like Huntington's.
- What a great resource for the community. Well done Help 4 HD with filling another gap.

Help  
4HD

*Thank You Sponsors*



# *HD Resource Database*

The HD Resource Database is an interactive database where families impacted by HD look for resources like adaptive equipment, anti-discrimination information, caregiver support resources, eating safely, estate planning, family planning, end-of-life planning, financial planning, grief and bereavement, home health information, respite, placement, waivers, legal aid, nutrition, support services, mental health services, self-care, animal services, transportation services, and more. Families can also reach out to us through our Contact Us form if they have any questions or need assistance requesting services. Our social worker is working with these families case by case. We have already started accepting requests. So far, we have received requests for assistance for things like electricity, respite, and another request for support services to help them with the day-to-day struggles they are trying to navigate. We also receive requests for information like law enforcement training and support group information.



## Community Comments:

- My daughter participated in his research the summer. She just loved him!!! It was interesting to learn about this study. She wasn't exactly excited about the lumbar puncture but she was excited to know that she was helping to further research into HD.
- Good morning Vicki, I just wanted to send my appreciation and thanks to you and Help4HD for the police training information! I took one set to Dundee police and one set to Milan police. They both seemed very receptive (crossing fingers.... Ben was stopped by the police in Milan two days before I got them the information while he was out for a walk, apparently a resident called on him and thought he was intoxicated or on something). I had to get extra from you because the week before I gave my packet to a friend in Adrian who needed it. Thanks again for ALL you do!! Its so very important and helps to keep our HD loved ones safe and the community in which they reside informed!!
- Can't wait to listen. This radio show has helped me so much. It is where I get my all my information about what my daughter is going through and what is to come for her in the future. .
- Chris and Lauren another amazing show! You are both brave fighters and warriors and don't feel like you're failing if you need to take a rest. I appreciate the advocacy but you need to look out for you too. I loved hearing you Lauren giving support to Chris. Chris I appreciated once again your openness throughout and the update on vaccinex and your visit to wave. I can also relate to the being on the doorstep or maybe at beginning of symptoms. So I'm with you guys about going to need a drug that helps when you've already got some symptoms. I want to continue living with HD as long as I can too!

# Help 4 HD Live!

Help 4 HD Live! is Help 4 HD International's longest-running program and the only weekly podcast specifically for Huntington's disease at this time. It just wrapped up the year with its 596th episode. Help 4 HD Live has covered topics such as clinical trial updates, personal stories, HD resources, support services, advocacy, caregiver support, care, and so much more. We are proud to have started the first-ever podcast for HD/JHD that is listened to worldwide and to have kept it running for 12 years.



**Help 4 HD Live! presents...**

**December 2023**

**Podcast Lineup**

Date	Day	Topic	Guests
07 DEC	THURSDAY	Help 4 HD 2023	Katie Jackson and Katrina Hargill join Lauren to talk about the 2023 programs & looking forward to 2024.
14 DEC	THURSDAY	Sage Therapeutics	Jennifer Bilet from Sage Therapeutics joins Lauren to talk about the clinical trials they are doing for HD.
21 DEC	THURSDAY	HD Unout, Ep. 10	Advocate Leah (Beller) Wittsche joins Lauren for the 10th episode of HD Unout.
28 DEC	THURSDAY	Christy Dearian	Author Christy Dearian joins Lauren to talk about the book she is putting together for the HD community.

**Thank you to our sponsors:**

teva, NEUROCRINE BIOSCIENCES, GRIFFIN FOUNDATION

**Help 4 HD Live!**

**Dec 28th, 2023**  
GET SOCIAL WITH US  
HD UNOUT, EP. 10 WITH LEAH B. WITSCHKE  
AT 4:00 PM

**Dec 21st, 2023**  
GET SOCIAL WITH US  
LIVABLE LIVES WITH CHRISTY DEARIAN  
AT 4:00 PM

**Help 4 HD Live!**

**Nov 2nd, 2023**  
GET SOCIAL WITH US  
USING MRIS IN HD RESEARCH WITH DR. KILLIAN HETT  
AT 4:00 PM

**Oct 12th, 2023**  
GET SOCIAL WITH US  
HD MYTHBUSTERS: GENERATION HD2 WITH RITA GANDHY  
AT 4:00 PM



## Community Comments :

- Thanks so much for sharing! A lot of good insight for families.
- This episode truly shows the generational trauma HD brings families. It is a hard episode to watch to see how much the system fails our families impacted by HD, but we are thankful to Jolie for being willing to tell her story for more awareness so people don't feel alone.
- Thank you, has been on my mind a lot lately, mainly for my children's protection. Thank you for talking openly about it.
- This is a struggle that isn't openly talked about. Thank you for doing a TV show on dating when you have HD in your life.

# Help 4 HD TV

Help 4 HD TV wrapped up the year by airing its 239th episode. Help 4 HD TV covered topics in 2023 like clinical trial updates, HD resources, caregiver burnout, guardianship, social security, cognitive issues in HD, talking about HD to children and the public, advocacy, eating safely, dating and HD, brain donation, youth and social connections, awareness campaigns, genetic testing, long term care, research updates, estate planning, loneliness, FDA talk, living with chorea, living with cognitive impairment, psychiatric symptom management, crisis intervention, feeding tubes, message banking, and more. Don't forget to like the videos, subscribe to the channel, and ring the bell for notifications when Help 4 HD TV episodes are released.



Thank You Sponsors





## Community Comments :

- So many wonderful, caring, and compassionate people all around the entire event!!! We had such an amazing time and can't wait to see everyone again!!
- Phenomenal as usual!!
- Informative updates!
- So appreciate the update and clarifications to help us understand the work done and being done.
- Thanks Help4HD for the great virtual day!
- Thank you so much! Great presentation!!
- Congratulations on a successful, informative, captivating day.
- It was excellent, so much info to take in.
- Great job. It was seamless and easy to access.
- Thank you for our HD/JHD package Help 4 HD International.
- Thank you Help 4 HD Katie Jackson and Katrina Hamel we got our swag box Lupe loves his new hat.
- It's so important that your support person has their own support within the community as well. This education Help 4 HD does is so important.

# HIPE

## *Highly Interactive Participant Education*

Help 4 HD hosted four HIPE days in 2023. We started the year with our first virtual HIPE on February 28 with the theme “Yes, NO, Maybe SO.” We were thankful to Dr. Erin Stimming, Dr. Karen Anderson, Emille Piechota, and Joie Hucka for being on our HIPE panel. We then partnered with Fundacion Huntington, Puerto Rico, to host our first in-person HIPE of the year in San Juan, PR. Then we hosted the second virtual HIPE with the theme “HD Community Videos~Experts Respond.” We would like to thank Dr. Bonnie Hennig-Trestman, Dr. Sam Frank, and Erika Boulavsky for sitting on our HIPE panel for our first try bringing in community videos for a whole HIPE session. We wrapped up the HIPE series with an in-person HIPE in Detroit, MI.





## Community Comments:

- It definitely helps to talk to someone who really understands this awful disease. I received the packet of information....so much good stuff and great resources. I really appreciate it! It will all be incredibly helpful!
- Would love 3 of the HD Id cards. My mother has HD and I would love to put this on all of our vehicles.
- I received the package this weekend! I just wanted to thank you for all your help. I truly appreciate you helping me advocate for families impacted by Huntingtons Disease in my community. I would love to participate in any other activities you have in the future. Thank you again.
- Thank you for sending the law enforcement packet. My step father has HD and I want my local police department to have this information. I plan to deliver it in person and speak to their mental health officer. Thank you Help 4 HD for providing this very important information.
- Hi Vicki!! I received my package with the information about the LEEP program. Thank you sooo very much. We don't have anything like this in my area. This program is so important especially since I'm a 3rd generation HD patient. Help4HD is the only organization that I know of that has this program and it's amazing.
- Good morning Vicki, I just wanted to send my appreciation and thanks to you and Help4HD for the police training information! I took one set to Dundee police and one set to Milan police. They both seemed very receptive (crossing fingers.... Ben was stopped by the police in Milan two days before I got them the information while he was out for a walk, apparently a resident called on him and thought he was intoxicated or on something). I had to get extra from you because the week before I gave my packet to a friend in Adrian who needed it. Thanks again for ALL you do!! Its so very important and helps to keep our HD loved ones safe and the community in which they reside informed!!

# LEEP

## Law Enforcement Education Program

From North Carolina to Crisis Intervention International to International Association Chief of Police...

Help 4 HD International educates thousands of law enforcement and first responder agents nationwide about Huntington's disease. We also sent hundreds of law enforcement packages to families impacted by HD/JHD nationwide. These packages included HD ID cards, "Someone with HD is Onboard" window decals, and training tools to help them engage with local law enforcement and teach them about Huntington's disease.

### Individual with Huntington's Disease On Board!

In case of an emergency, please be aware that the individual:

- May not be able to speak or articulate pain or injury
- May not be aware of the situation
- May be resistant to any help from first responders
- May appear to be intoxicated or on narcotics due to symptoms of Huntington's disease



Thank You Sponsors:

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## Community Comments :

- Would be lost without this group.
- Through this support group we have found our tribe.
- The caregiver group is very helpful for me. I'm forever grateful.
- I feel like we have become a family that meets once a week.
- I don't know where I would be without my caregiver group.
- The caregiver group is a place we share our stories and experiences. I plan on coming to this group as long and as often as I can.
- It is so hard to find any help for JHD let alone anyone who understands. I am thankful for the group. I love everyone in it.

# Help 4 HD Support Groups

Help 4 HD International hosts a weekly virtual support group for HD caregivers every Tuesday. We also host a JHD Caregiver support group on the first and third Tuesday of every month.

We have watched these support groups grow over the last three years. We will be adding new support groups in 2024. We have heard the community call these virtual support groups their lifelines. They have found their tribe within the group. The support, love, community, and knowledge shared within these support groups every week is truly unique. Together, we are stronger, and support groups are the way not to feel so isolated and alone.



**HD CAREGIVERS**  
VIRTUAL SUPPORT GROUP

**TUESDAYS**  
**2PM**

Help 4HD CONTACT US FOR LINK  
www.help4hd.org

teva

This graphic features a dark blue background with three circular icons on the right: a calendar, a hand holding a red heart, and a hand holding a small object. The text is white and yellow.



**JHD CAREGIVERS**  
VIRTUAL SUPPORT GROUP

**1ST & 3RD**  
**TUESDAY**  
**5PM**

Help 4HD CONTACT US FOR LINK  
www.help4hd.org

teva

This graphic features a purple background with three circular icons on the right: a puzzle piece with the word 'support', a dog, and a person. The text is white and yellow.

*Thank You Sponsors*





## Community Comments :

What have you had to reduce due to a lack of HD awareness?

Community Responses:

~My daughter was nearly strip-searched at the airport when she was probably because her hip moved a little when she was going through the body scanner. She was maybe 70 lbs and wearing a t-shirt and leggings...she couldn't have been hiding something on her body if she wanted to. We explained that she had HD and they wouldn't give us the time of day.

~My daughter's father was kicked out of an establishment because they thought he was extremely drunk, but it was just Huntington's. Even after trying to explain, they wouldn't let him back in.

~ My husband was pushing a shopping cart in Walmart with our little girl, who was about nine months old at the time. These women started whispering loudly so we could hear, saying they couldn't believe I let that guy who was "obviously very drunk" push my daughter in a cart, and hopefully, I didn't let him drive too.... Their children were running up and down the aisles like heathens. My husband didn't want me to, but I turned around and said, at least my kid is well-behaved, and I know where she is ... oh and also, my husband is sick with a terminal neurodegenerative disease called HD and not drunk at all. They were dumb founded.

~My husband also was forced to take a breathalyzer the day before his diagnosis was received, we were driving home from our last hurrah dinner in case the results were bad and had a taillight out. The cop pulled my husband over, told us about the taillight, asked if he had been drinking (he hadn't), and then made him take a breathalyzer unfortunately, that officer ruined our last hours of the before-diagnosis period.

# HD Awareness Month

This year, Help 4 HD sent hundreds of HD Awareness boxes nationwide. These boxes had awareness items in them, like pop sockets, straws, awareness cards, window clings, and blanket/pillow combos. The community took pictures holding the awareness cards, answered the questions, and posted them all over social media, creating an amazing HD awareness campaign.



Thank You Sponsors





## Community Comments :

- Thanks for being brave and putting your story out there, Charlie! You help the rest of us understand your world.
- I love this !!! Thank you Eyes Ears Nose and Paws for supporting JHD. Olivia you are beautiful and I can't wait to see this through! Looking forward to the next article.
- Rarely do we get positive news reported within our community. So this is a good article. Respectfully, I think it's fair to look at who's leading us up top into fairly consistent failure year after year parity act or research.
- Great news articles!
- More disappointment for the HD community. BUT I know this community will persevere and move forward until we ACHIEVE the end point.
- Beautifully said! I enjoy reading this page very much!

# *The Huntington's Post*

The Huntington's Post is our online blog that brings informative reporting to our Huntington's disease community. We have covered topics like clinical trials, reports on events, genetic testing, caregiver support, press releases and many other topics. We also open up The Huntington's Post for community members to write as well. Community members have submitted poems, personal stories, and other topics that have been published in The Huntington's Post.

This year we introduced "Community Questions" to The Post. This is a way for the community to engage and talk about a specific question pertaining to the HD journey. This new series started conversations within the community. Help 4 HD International was overwhelmed by the response to the Post this year by community and partners during HD Awareness Month. The Post was a platform for the community to tell their stories and read others like their own.



Thank You Sponsors





# Community Comments :

What part of Help 4 HD Symposium did you find most beneficial?

- The personal stories that were shared of actual lived experience of HD
- I like the talks about slowing the progression of HD. I am going to look more into those trials.
- Covering every aspect of the disease from onset to end of life
- Meeting other people going through the same thing as us
- The panel with all the different doctors was my favorite part
- I am just starting to learn about Huntington's disease so every part of this event was important to me. All speakers helped me learn so much. Thank you!
- I loved the HIPE. It was exceptional. I really enjoyed all the individual presentations in between speakers.
- Grief and Guilt was my most beneficial talk for me.
- I loved all the families there and the clinicians that were enthusiastic and were available.
- We know we aren't alone after this event. To see so many people trying to fight this event.
- Hope! We got hope today.
- Help 4 HD gets it
- The different types of sessions were helpful. Research to end of life a lot was covered depending on where you are with HD.
- The most beneficial part of these events is being with people living the same experiences you are.
- I liked the breakout sessions. I spent most of the time in that room. They were all beneficial.

# Symposium

This year, Help 4 HD International hosted its annual symposium in San Diego, CA. Hundreds of HD community members came from across the nation to listen to talks specific to HD/JHD and to join two evening events full of talk, laughter, dancing, great food, and community. We would like to thank all of our community members who took long flights to join us and all of our professionals who came from across the nation. Finally, thank you to all the sponsors who believed and understood the great need and impact this annual event makes on our community. Without you, this special event could have never been such a great success as it was.



Help  
4 HD



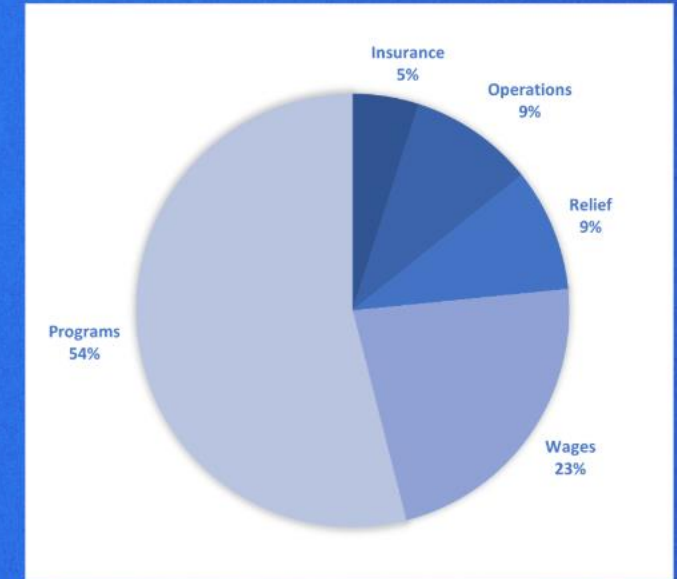
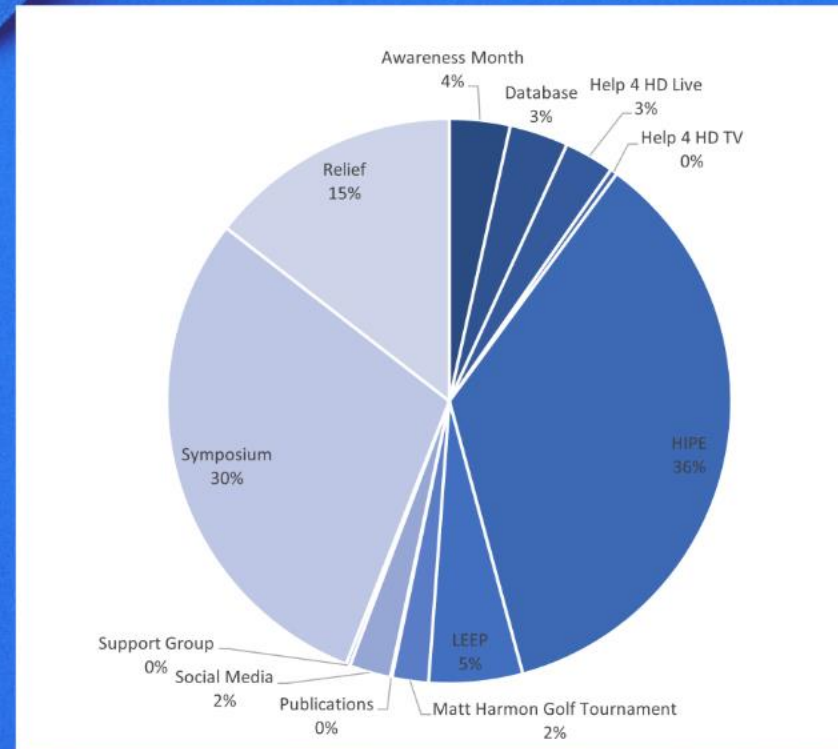


# *Help 4 HD International Financial Overview 2023*

*(This report was ran on December 26, 2023)*

## Programs

Awareness Month	\$13,210.51
Database	\$12,836.82
Help 4 HD Live!	\$10,893.00
Help 4 HD TV	\$1,503.40
HIPE	\$135,829.49
LEEP	\$20,442.88
Matt Harmon Golf	\$7,931.95
Publications	\$353.10
Social Media	\$9,000.00
Support Group	\$895.56
Symposium	\$112,386.60
Relief	\$55,165.85
Grand Total	\$380,449.16



## Expenses

- Insurance \$29,763.24
- Operations \$56,099.57
- Relief \$55,165.85
- Wages \$136,074.15
- Programs \$325,283.31
- Grand Total \$602,386.12