

Help 4 HD International

Educating the World About Huntington's and Juvenile Huntington's disease

The logo features the word "Help" in a large, blue, serif font. Below it, the number "4" is rendered in a bright blue, 3D-style font with a vertical blue and white striped bar passing through its center. To the right of the "4" is the word "HD" in the same blue, serif font as "Help". The entire logo is set against a white rectangular background, which is itself on a dark blue field. Decorative curved lines in light blue and yellow are visible in the upper right and lower left corners of the page.

Help
4HD

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Help 4 HD International

Our Mission

Help 4 HD's mission is to educate the world about Huntington's disease and Juvenile Huntington's disease. The aim is to serve our community and provide information, education, and resources.

Our Goal

Help 4 HD's goal is to continue establishing strong roots in the underserved communities and to seek out new underserved areas to educate, help, and serve.

Our Vision

Help 4 HD envisions a world where everyone knows what Huntington's disease and Juvenile Huntington's disease is; 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.

Family First

Help 4 HD is focused on helping HD families by bridging communications and partnering with institutions, industry, and professionals from every discipline. Help 4 HD's philosophy is always "Family First". Seeing as how Huntington's disease is a genetic disease, we know that focusing on supporting the family as a whole with education and resources is our utmost priority.

2023 Programs and Projects

HIPE (Highly Interactive Participant Education)- This year, Help 4 HD International (H4HDI) will host four Help 4 HD Education Days. These events will be one-day conferences for the Huntington's disease community to come and hear keynote speakers speak on clinical trials, care, science, and services. We will have a neurologist, a psychiatrist, and a social worker on every education day, as well as our HIPE (Highly Interactive Participant Education) panel. We will be hosting two virtual HIPE days and two in-person HIPE days. The first in-person will be held in March in San Juan, PR, and the second will be held in Michigan.

The response from the community about virtual HIPE has been so positive we have decided to hold two virtual HIPE days next year in between the in-person HIPE events. That way, our entire community can participate in this program if they choose.

The in-person education days will have breakfast; then, the day will open with two keynote speakers. We will then host a lunch and finish the day off with two more keynotes and our HIPE panel. We will also have exhibitors as well as resources and information at these events.

On every education day, we will have the professionals give an overview of Huntington's disease and the symptoms associated with HD and symptom management. We will also provide research updates during the education days. This will allow the patients and caregivers to hear about research and the possibility of new treatments coming soon to help with Huntington's disease and the symptoms associated with Huntington's disease. We want to make sure that the patients and caregivers leave the education day with a better understanding of Huntington's disease and some coping mechanisms and ideas for symptom management.

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Help
4 HD

2023 Programs and Projects

Help 4 HD International Annual Symposium- Help 4 HD International will be holding its annual symposium in 2023 in San Diego, CA, on October 13th and 14th.

Help 4 HD International Annual Juvenile Huntington's Disease Symposium- This year, Help 4 HD International will be hosting its annual two-day symposium in San Diego, CA, in October. This symposium will be run concurrently with our annual HD symposium but will be its own event.

Help 4 HD International Support Groups- We host weekly support groups for the caregiver as well as biweekly support groups for JHD families.

Help 4 HD TV- Help 4 HD TV came out of the pandemic. This is a weekly show that runs on YouTube.

Help 4 HD Live!- Help 4 HD Live! is the program that launched Help 4 HD International back in 2010. Huntington's disease families live with emotional, physical, and financial devastation. The disease often makes families become isolated. They are unable to leave their homes, which forces them to find education and support virtually. We found BlogTalk Radio (BTR) and established "Help 4 HD Live!" from our kitchen table. It was a nonprofit bringing education and resources from our homes to our community in the comfort of their own homes. This show grew to an international listenership. Help 4 HD International watched this small radio show grow to over 150k all-time listenership since the beginning. All radio shows are archived and available on iTunes, iHeart Radio, and Spotify, as well as BTR.

Help 4 HD Law Enforcement and First Responders Education Program- Our LEEP program began in 2014 when Help 4 HD International exhibited at its first International Association of Chiefs of Police (IACP) conference. While there, our education team came face-to-face with hundreds of law enforcement agencies from around the world. Our team was able to talk about the nuances of Huntington's disease and why it's important for law enforcement agents to understand the symptoms and characteristics of HD.

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Huntington's Disease Family Relief Fund- This relief fund was created to help HD/JHD families with emergency costs that come up that they are unable to pay. We have used the Family Relief Fund to purchase comfort devices like weight blankets or cooling blankets. We can help with things like household quality-of-life bills, quality-of-life essentials, and other emergency assistance with needs that come up. We have also helped families through natural disasters.

The Huntington's Post- *The Huntington's Post* is our online newspaper that brings informative reporting to our Huntington's disease community. We have covered topics like clinical trials, reports on events, genetic testing, caregiver support, guilt, grief, resilience, press releases, family planning, psychiatric symptoms, cognitive symptoms, chorea, law enforcement, public impact, and many other topics.

May is HD Awareness Month Project- This year, Help 4 HD International will be providing 500 families with free May HD Awareness packages. These packages will include four items; a T-shirt with sayings phrases like: "IM NOT DRUNK I HAVE HUNTINGTON'S DISEASE, ASK ME ABOUT IT," awareness items for the cars like awareness decals, awareness items for the home like window stickers and signs to put up for neighbors to learn about HD, phone covers, and more.

HD Resource Database- This year Help 4 HD International will launch a database for our Huntington's disease community. This will be an interactive database where individuals impacted by HD can post resources that have helped their families along the way that will help our future generations to come. When using the database, you will be able to search for keywords pertaining to what you are looking for. There will be sections on benefits, adaptive equipment, articles, etc.

