

Help 4 HD International 2015 Annual Report

Help 4 HD International

Educating The World About Huntington's Disease

A letter from leadership:

Help 4 HD International is working every day to retain current programs and to develop new programs that will support our Huntington's disease community. A tagline that Katie Jackson, CEO of Help 4 HD International, came up with for Help 4 HD International a couple of years ago is: "Help 4 HD International is in the trenches with the people because we are the people."

We are a grassroots patient representative organization that was created for the sole purpose of educating the world about Huntington's disease. We have worked hard this year to fulfill our mission by continuing to bring relevant information through our radio show, educating law enforcement and first responders, opening a Huntington's disease resource center, hosting awareness events, and much more. We are here for our Huntington's disease community, standing beside you, fighting the fight every day. We may be tired, but until the cure is found, there is work to be done. Help 4 HD International is fighting every day to be the last generation to live with Huntington's disease in the way that our generation and past generations have been forced to do. We would like to thank all of our donors and sponsors for making it possible for us to continue to support, educate, and inspire!



Katie Jackson
President/CEO



Katrina Hamel
Vice President

Our Mission:

Help 4 HD's mission is to educate the world about Huntington's disease and Juvenile Huntington's disease through its multimedia communications platform and through community outreach efforts. The aim is to serve resource centers to provide information, education, resources and care.

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 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.

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!" Nothing is more important than facilitating safe and healthy families, and the way we do that is through education, outreach, and support.

Our Commitment to the HD Community:

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 and connecting credible care professionals with the community is our top priority. Now, with several Help4HD support groups, what started out as a California association has become a global effort.

Help 4 HD is ready and willing to go where no one has gone before. Individuals with HD need help the most because they are sick, isolated, alone, and estranged from their families through no fault of their own. They are in situations where there is little understanding about the HD condition.

Help 4 HD knows that there are thousands of HD families who are not getting the help they need and deserve. The purpose of the organization is to find the families who are devastated by HD and provide them with education and assistance.

Help 4 HD International's Programs

- Ambassador Program (115) world-wide
- Caring4HD Affordability Shop & Resource Center
- Clinical Trial Support Platform
- Help4HD Live! Radio Broadcasting since 2010
- Help4HD Publishing: Newspaper, Magazine, Books
- Help4HD Relief Fund & Wilderness Kids Relief Fund
- H4HDiRegister: patient registry, surveys, polls
- JHD Research Initiative: Funding research for JHD
- JHD Memorial Fund
- Law Enforcement and First Responders Education
- Live Events: Symposia, Conferences, Walks, Runs, Education Days, HD Awareness Days
- Support Groups: CA, FL



Ambassador Program: Help 4 HD International Ambassador Program has over 115 volunteers participating at this time. Ambassadors are able to advocate for Huntington's disease in many different ways. Some of the projects ambassadors worked on in 2015 were law enforcement education, letter writing to local officials, being interviewed on Help 4 HD Radio, hosting awareness and fundraising events, running awareness campaigns, and much more.

Caring 4 HD Affordability Shop & Resource Center: This year, Help 4 HD International opened the very first thrift store to benefit the Huntington's disease community. Within the thrift store is also a Huntington's disease resource center. We sell lightly used household items and clothing. Families that are living with Huntington's disease can go to the store any time and get any clothing or household items they need at absolutely no cost to them. We also have resources available to the Huntington's disease community available at the store. Huntington's families can come and get help filling out their applications for benefits as well as getting publications on support resources, clinical trials, HD education tools, and can also get medical supplies like medical straps or adult diapers. All of this is absolutely no cost to families living with Huntington's disease.

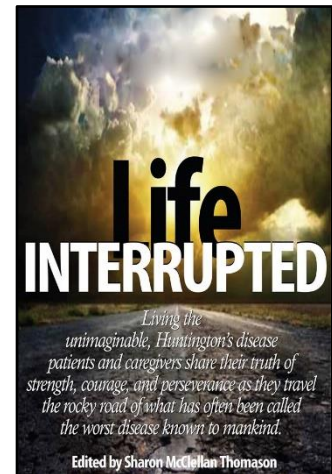
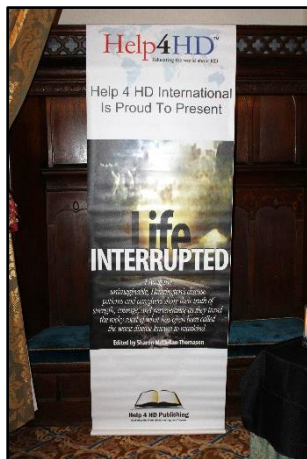


Clinical Trial Support Platform: Help 4 HD International works directly with sponsors or sites that are conducting clinical trials. Help 4 HD discusses with the sponsor or site the challenges that our community faces when it comes to enrolling and retaining clinical trials. We also talk about solutions that will help support the individual living with Huntington's disease as well as the caregiver that is bringing the individual to the clinical trial throughout the whole process.

Help 4 HD Live! Radio: Help 4 HD Radio aired its first show in 2010. Now with over 98,000 listenership and over 230 archived shows available on iTunes and BlogTalkRadio, this show has been a great tool to bring important and relevant information to our Huntington's and Juvenile Huntington's disease community.

Help 4 HD Live! *presents...*

Help 4 HD Publishing: Help 4 HD International has many publications and informational brochures as well as a newspaper and magazine. We just published our first book, *Life Interrupted*, in July 2015. This book is a collection of memoirs written by 12 patients and caregivers living with HD and JHD. This has been a great book to teach care providers, scientists, industry, and the public about what it is like to live with Huntington's and Juvenile Huntington's disease.



Wilderness Kids Fund and Family Relief Fund: This year, by Help 4 HD's Family Relief Fund partnering with the Wilderness Kids Fund, we were able to give \$3,400 in relief to families living with Huntington's disease. Help 4 HD facilitates a wonderful program, The Wilderness Kids Fund. This fund holds a drawing every six months for families in need that have entered their names into the drawing. This program, along with the Help 4 HD Family Relief Fund, has brought assistance to HD families in 2015. This year, with the Wilderness Kids Fund and matching funds from Help 4 HD, we were able to help four JHD families as well as other HD families through the semiannual drawing.

Help 4 HD iRegister: This program has a patient registry as well as enabling us to run polls and surveys for different doctors and scientists who are trying to understand something about Huntington's disease a little better. We have also run law enforcement education surveys through this program as well. We also ran requests for our Law Enforcement in a Flash program through this portal.

JHD Research Initiative: Help 4 HD International set up this initiative to bring awareness as well as funds to JHD research. This year, Help 4 HD International held two walks specifically for Juvenile Huntington's disease where all net proceeds from those walks went directly to JHD research. We have also supported the efforts of JHD studies through this program.

JHD Memorial Fund: This program was set up for families that have lost their children to JHD. All donations that are received through this memorial fund go directly to JHD research. We started this fund in December but were able to donate \$775 from the fund to close out 2015. This fund will continue in 2016, and we will continue to donate all proceeds from the fund to JHD research.

Law Enforcement and First Responders Education Program: This program was set up to educate law enforcement and first responders about Huntington's disease. Our Law Enforcement Education Program (LEEP) team attended the annual Florida Police Chiefs Conference in January 2016, as well as conducting advanced officer training courses up and down the state of Florida. We also launched our

"Law Enforcement Education in a Flash"

component to this program. Help 4 HD loaded flash drives with of informative brochures, a PowerPoint, and videos of individuals living with HD. We then started handing these out at conferences and trainings as well as shipping these flash drives to police/sheriff's departments and first responders across the nation. We ask that the departments use this education tool in their advanced officer training courses. That way, we are

getting this information directly to the public safety officers that are on the streets as well as in facilities.



Help 4 HD International 2015 Events

Help 4 HD International Symposium 2015, Riverside: Help 4 HD International held our second annual symposium in Riverside, California. This event brings Huntington's disease community face to face with experts in the disciplines of neurology, psychiatry, research, and other areas that affect our families. We believe that knowledge imparts hope, and our Riverside symposium did just that.



Sacramento JHD Walk: This year, Help 4 HD International hosted the first walk ever that was specifically focused on JHD awareness and support for JHD research. Help 4 HD was able to give \$12,000 net proceeds from this walk to UC Davis research that is focused on JHD.

Help 4 HD International Scholarships: Help 4 HD International gave scholarships to mothers who have children living with HD/JHD to fly to the first ever JHD walk and meet for the first time in person. Help 4 HD International spent over \$4,000 last year in scholarships to bring HD/JHD families together.



HD Awareness Day: Help 4 HD International hosted the first annual HD Awareness Day in Lompoc, California. The community came out to learn about HD/JHD. We had support services, resources, games, live music, and a day filled with Huntington's disease awareness!



San Diego Nik's Run 4 HD: This year, Help 4 HD International hosted a walk in San Diego where all net proceeds made went directly to research. Help 4 HD International was able to donate \$5,365 to research from this event! Thank you, Melissa Feria, for making this event a great success.



Help 4 HD International Attends Patient Focused Meeting at the FDA: Help 4 HD International sent patients from all over the country to attend the patient focused meeting at the FDA. There, Help 4 HD International advocates shared with the FDA their stories of living with Huntington's disease and Juvenile Huntington's disease and the need to expedite treatments and therapies for those who are living with HD/JHD.



Thank You to the Sponsors, Donors, and Exhibitors
for Help 4 HD International's Events and Programs!

HD Awareness Day 2015 - Sponsors & Participants



Help 4 HD International Riverside Symposium Sponsors and Exhibitors



JHD Kids Walk Sacramento Sponsors and Donors



Nik's Run 4 HD San Diego Sponsors and Donors



Help 4 HD, International Budget FY 2015

REVENUE

General Fundraising & Events	25,031.40		
General Contributions	6,764.12		
Direct Public Support	9,922.65		
Gifts in Kind - goods	12,795.00		
Sponsorship	170,333.00		
TOTALS	\$224,846.17		

EXPENSES

General Operations	24,713.84		
Fundraising Expenses	39,639.73		
Facilities and Equipment	14,570.84		
Legal/Accounting/Insurance Fees	5,953.93		
HD Relief Fund	3,400.00		
Education Expenses	34,124.03		
Marketing/Advertisement/Website Expenses	10,785.76		
Salaries	38,291.67		
TOTALS	\$171,479.80		

2015 Net Non-profit Income

\$48,946.37

In 2015, Help 4 HD International was able to donate \$18,140 to Juvenile Huntington's disease research.

In 2015, Help 4 HD International gave over \$3,400 to Huntington's disease families through our Help 4 HD International Family Relief Fund and the Wilderness Kids Firewood Program.

Asset Type	Amount
General operation	\$29,134
Fundraising expenses	\$39,640
Facilities & Equipment	\$14,571
HD Relief	\$3,400
Education	\$34,124
Marketing/Advertising/ Website	\$10,786
Salaries	\$38,292

2015 H4HDI Allocations

