A Message From the President/CEO

Everyone at Help 4 HD International is working hard every day to educate the world about Huntington’s disease. We, as a company, 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 feel will truly help our community when navigating their very hard journey, living with Huntington’s disease.

Help 4 HD International is the home of the very first radio show created for the Huntington’s disease community. We will continue to bring meaningful, credible information to the Huntington’s disease and Juvenile Huntington’s disease community in the comfort of their own homes. With over 113,000 all-time listens and over 310 archived episodes available on iTunes and BlogTalkRadio, “Help 4 HD Live!” has been a well-utilized tool for the HD/JHD community to come and get information. This year, Help 4 HD Live is now also available on Spotify and iHeart Radio.

This year, Help 4 HD International attended and exhibited at two law enforcement state meetings in California and Louisiana. We continue to go to local law enforcement advanced officer training courses to help officers and first responders understand Huntington’s disease a little better. We continue to send out our Huntington’s Disease Law Enforcement Education in a Flash education tool across the nation. We wrapped up our law enforcement program again this year by hosting our annual Strike Out HD tournament, where law enforcement and fire agencies come from all over and compete in a softball tournament to raise funds and awareness about Huntington’s disease.

In 2019, Help 4 HD International was able to help many Huntington’s and Juvenile Huntington’s disease families in need. Our Family Relief Fund is a program we all believe is significant at Help 4 HD. We know that many families impacted by Huntington’s disease live with financial devastation. Our relief fund has helped families with electric bills, food, gas, travel expenses to appointments, and much more. We also expanded this program in 2019 to help with relief in Venezuela and Colombia through Factor-H. We also made sure that we ran our holiday programs in 2019 for our families in need. We provided cards for families to buy their holiday meals as well as our toy program for children that live in homes impacted by HD.

In 2019, we ran our HIPE (Highly Interactive Participant Education) program. Help 4 HD conceived this interactive program in response to the needs of families within the HD community. Together, caregivers, patients, and medical professionals discussed scenarios that impact families and, as a group, suggested strategies and tactics for dealing with these issues. This program allows the community, particularly families that have tried other options without much success, to look at possible solutions to common problems. We held our HIPE Days in 2019 in Texas, Puerto Rico, and Kansas.

We wrapped up our year by hosting our annual symposium in Las Vegas, NV. We had speakers come from all over the nation and give us updates on research as well as talk about ways to navigate our journeys with challenges we deal with along the way. We partnered with HDYO (Huntington’s Disease Youth Organization), who planned a day of special activities for youth who were attending the symposium.

We work hard at Help 4 HD International so that future generations do not have to live with Huntington’s disease like our generation and past generations have been forced to do. Our dream is to see unawareness become awareness, and the uncompassionate become compassionate. We work through education to make this dream a reality. We are in the trenches with the people because we are the people, and we will continue to fight with passion and diligence. We are 100 percent committed to supporting our Huntington’s disease community and working every day to educate the world about our community and the many challenges we face.

—Katie Jackson
Help 4 HD International’s Board of Directors

Katie Jackson
California
Katrina Hamel
California
Michael Sabado
California
Sharon Thomason
Florida
Vicki Owen
Florida
Stacey Sargent
Georgià
Tammy Miller
Iowa
Terry Tempkin
Washington

OUR STORY

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, Help 4 HD Radio, Help 4 JHD Radio, symposia, conferences, publications, and support groups, 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 strong roots in the 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. Now, with several Help 4 HD support groups and over 100 ambassadors, what started out as a California association has become a global effort. 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.
Some Topics and Guests on Help 4 HD Live in 2019
EHN
Speech Therapy Research
Suicide Prevention Kate Miner
Fall Prevention HNDC
Guilt and Grief Ed Wild
chANGE-HD Dr. Thomas Bird
IVF PDG Factor-H
Caregiver Support UniQure
Racer John Paul Jr. Victor Sung
HDYO And many more...

Help 4 HD Live!, the longest-running radio show focused on Huntington’s disease wraps up its 9th season. Thank you, for an education grant from Teva Pharmaceuticals and the Griffin Foundation, for making this show possible.
Help 4 HD International
Law Enforcement Education Program (LEEP)
and EMT/First Responders 2019

Some places, this year, our law enforcement training kits have been sent to New York, Montana, Arizona, Nevada, California, Texas, Florida, West Virginia, Wisconsin, Iowa, Virginia, Colorado, Kansas, Washington, Missouri, Louisiana, and Georgia for local law enforcement and first responder training. Thank you to all the families that have taken the time to help educate their local law enforcement and first responders about Huntington's disease.

For more information or to download first responder training videos and brochures, please visit: https://www.help4hd.org/programs

THANK YOU TO OUR SPONSORS
Help 4 HD International Family Relief Program

In 2019, Help 4 HD has given $16,446 to HD/JHD families
To help relieve some of the financial burden
Within our community.

• Utility Bills
• Medications
• Gas
• Food
• Holiday Meals
• Holiday Gifts
• Clothing
• And Other Relief

Relief Sent To:
• Colombia
• United States
• Canada
• Venezuela
• England

Our HD/JHD Relief fund has been made possible by a generous grant from TEVA, but also from all of our community supporters. Thank you, to everyone who ran a Facebook fundraiser, donated to our relief fund. Specifically, and to those of you who have given donations in your family member’s name. We will always honor the wishes of your donation, every penny helps and we are so thankful!
Help 4 HD conceived this interactive program in response to the needs of families within the HD community. Together, caregivers, patients, and medical professionals versed in HD will discuss scenarios that plague families and will, as a group, suggest strategies and tactics for dealing with these issues. This will allow the community, particularly families that have tried other options without much success, to look at possible solutions to common problems. It will also allow professionals to learn more from the community about the issues we face. Help 4 HD envisions a group of people with similar but different backgrounds sharing ideas about situations that are often difficult to handle. Caregivers can support others in similar positions, and professionals can support these conversations with added direction and advice. We see this program as a way of offering to families within the HD community and to medical professionals a “tool kit” for dealing with a wide range of issues.

Highly Interactive Participant Education
Some of Help 4 HD International Events in 2019

Help 4 HD International held many events in 2019 like Casino Night Out 4 HD, Ponies For A Purpose, Matt Harmons Annual Golf Tournament, Cory's Crusade, and Strike Out HD. Help 4 HD International holds to our promise that 100% of all net proceeds raised at all Help 4 HD International's event goes where the fundraiser coordinator chooses. This year, Help 4 HD International, because of the efforts of our fundraising coordinators, were able to give funds to UC Davis of California and the University of Iowa. Some monies raised by events by the event coordinators' wishes went into Help 4 HD programs like our Law Enforcement Education Program (LEEP) and our HD Family Relief Program. Help 4 HD International would like to thank all of our event coordinators this year for making it possible to continue to support important programs and research for our HD/JHD community.
Help 4 HD’s annual symposium was held Saturday, October 12, at the Palace Station in Las Vegas, NV. The symposium began with a meet-and-greet Friday night that featured hors d’oeuvres, DJ, dancing, and great conversation!

Everyone was invited to attend the evening reception and award ceremony. The reception included hors d’oeuvres, nonalcoholic beverages, dessert, a cash bar, and live music and dancing. Help 4 HD International presented checks to UC Davis and the University of Iowa.
Life Interrupted: Published in 2015, Life Interrupted is a collection of memoirs written by 12 patients and caregivers living with Huntington’s and Juvenile Huntington’s disease, and includes an Afterword by Jimmy Pollard. The book may be purchased today for $20. It is also available on Amazon, Kindle, and Nook. For ordering information, please visit http://help4hdlifeinterrupted.weebly.com/.

Life Interrupted, Volume 2, Volume 2 of Life Interrupted continues the stories of caregivers and patients living with Huntington’s and Juvenile Huntington’s disease. This volume is a collection of memoirs from ten people in Australia, Canada, and across the United States. It is available on Amazon and Kindle.

I Fight For...Understanding, Published in May 2017, as part of Help 4 HD International’s “I Fight for” campaign for HD/JHD Awareness Month, I Fight for Understanding is a collection of 31 days’ worth of tips for coping with Huntington’s disease. It was written by Ginnievive Patch, who was a caregiver for her mother-in-law and ex-husband, and two sons, all of whom have HD. The book is available on Amazon and Kindle.

Living with Huntington’s Disease, Author Sharon Thomason shares her experiences and what she has learned along the way, including how to advocate for your loved one and the grief and resilience that goes hand-in-hand with living with HD. The book is available on Amazon and Kindle.
Help 4 HD International has successfully continued the following projects and programs throughout 2019:

**Help 4 HD Live!**
Our weekly podcast finished off the 9th consecutive year as the first and largest listened to show in the HD community. Topics included Caregiving Strategies, Research Updates, Personal Stories, Local Resources, Suicide Prevention, Mental Health Awareness, and more!

**L.E.E.P. (Law Enforcement Education Program)**
We handed/shipped out thousands of our flash drives with educational materials geared towards helping law enforcement and first Responders to better understand HD/JHD. We attended live law enforcement training events and also had law enforcement at our annual symposium to learn more.

**HD and JHD Family Relief**
This program is available because of a grant given to Help 4 HD by Teva, Pharmaceuticals as well as so many members of our community who have either received help in the past and would like to pay it forward, or because they know that there are minimal amounts of financial support to families facing financial devastation due to this disease.
H.I.P.E. (Highly Interactive Participant Education)
We were asked by families all over the U.S. to come to do this unique event, where families can ask tough questions, to experts, anonymously. We were able to provide families with a one night stay in a hotel in order to attend if they were unable to drive to and from the event in one day.

Events
We are so thankful to all of our volunteers who did an event this year, many of which have become annual events. The monies raised during these events always go directly where the organizer of the event chooses.

Annual Symposium
This year we were able to provide 20 hotel rooms for two nights to families who needed the support of our event and lived too far to drive to and from this event in one day. This year, we held our symposium in Las Vegas, NV, and it was our 6th annual event.

Publications
We continue to send out our unique brochures to families in the community to either assist them in educating the community or for a tool for everyday caregiving. We have four books published through Help 4 HD Publishing that continue to be top sellers on Amazon.
Help 4 HD International Income and Expense Report 2019

2019 HELP 4 HD INCOME

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2019 HELP 4 HD EXPENSES