

# Help 4 HD International

Educating The World About Huntington's Disease

5050 Laguna Blvd. 112 543

Elk Grove, CA 95758

916-698-0462

[www.help4hd.org](http://www.help4hd.org)

## ANNUAL REPORT: A LOOK BACK AT 2017

### 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 grass-roots 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 important, credible information to the Huntington's disease and Juvenile Huntington's disease community in the comfort of their own homes. With over 100,000 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 International attended and exhibited at two law enforcement state meetings in Florida and Alabama. 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 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 2017, 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 very important 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 recognized our caregivers this year through a program called "A Cup of Coffee for a Caregiver." We also started our HD disaster fund when Hurricane Harvey hit Houston and supported HD families living in the area. We continued this program for Puerto Rico when Hurricane Maria hit and for Florida when Hurricane Irma hit. We were able to send funds to the Huntington Fundación Puerto Rico to help them help our HD families on the island. We also helped families evacuate out of Florida during Hurricane Irma. We also made sure that we ran our holiday programs in 2017 for our families in need. We provided cards for families to go buy their holiday meals as well as our toy program for children that live in homes impacted by HD.

In 2017, we piloted 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 first year of HIPE education days in: Sacramento, CA; Kirkland, WA; Atlanta, GA; Houston, TX; Cedar Rapids, IA; and Tampa, FL.

In 2017, we also started filming a documentary, *The Warriors, Fighting the Incurable Juvenile Huntington's Disease*. We have supported Juvenile Huntington's disease research since 2015. We decided we needed to take it a step further and tell some of the stories of our children who are living with Juvenile Huntington's disease. Our hope is that this film will bring JHD awareness as well as raising funds to support our JHD community and JHD research.

We wrapped up our year by hosting our annual symposium in Tampa, Florida. 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

# BACKGROUND INFORMATION

## History & Leadership

### HISTORY

**Help 4 HD International** began its mission to educate the world about Huntington's disease in May 2010, when founder Melissa Biliardi organized the first symposium and CME in Santa Maria, California. In June, the first support groups were formed and in November, the first online radio show was created to bring education and information to the HD community. Help 4 HD was incorporated and received tax exemption as a 501(c)(3) public charity in 2013. Now in its 7th season, Help 4 HD Live! has over 100,000 listeners and the world has free access to over 310 archived episodes available on BlogTalkRadio.com/Help4HD and iTunes. In September 2015, Help 4 HD opened its first affordability shop and resource center, Caring 4 HD, in Lompoc, California, to serve the underserved and to help HD families on the California Central Coast.

Help 4 HD is a grassroots patient advocacy organization, and as President Katie Jackson says, *"We are in the trenches with the people because we are the people."* The staff and volunteers come from diverse backgrounds: corporate and small business, sales and marketing, education, information technology, military services, communications, journalism, social work, counseling, healthcare, and hospitality, and all are personally affected by Huntington's disease. At Help 4 HD, the battle cry is "Never Give Up!" and the mantras are "Children Are First Priority," "Family First," and "Don't Wait—Do It Now!"

Help 4 HD International is a proud communications partner of the Huntington Study Group (HSG) and plays a vital role in connecting the HD community with research and industry, providing news about upcoming clinical trials and studies, broadcasting information through its multimedia communications platform, social media networks, and Help 4 HD Radio. Help 4 HD knows that without clinical trials, the HD community will never have treatments, therapies, or the cure. Help 4 HD knows that attending important advocacy meetings is paramount to pushing successful treatments and therapies through regulatory agencies, and its representatives are dedicated to attending these meetings.

### 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 the underserved areas with support groups and 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/JHD COMMUNITY:

All of Help 4 HD's 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.

### BOARD OF DIRECTORS



**Katie Jackson**  
President/CEO/Director  
katie@help4hd.org  
916-698-0462



**Katrina Hamel**  
Vice President of  
Operations  
katrina@help4hd.org  
805-623-3653



**Michael Sabado, MBA**  
CIO  
michael@help4hd.org  
925-884-3709



**Denise Hudgell, RN**  
CFO  
denise@help4hd.org  
402-699-9933



**Sharon Thomason**  
Secretary & Director of  
Education  
sharon@help4hd.org  
850-509-0532

# EVENTS 2017

## Florida Chiefs of Police Mid-Winter Training

Help 4 HD International Inc. kicked off 2017 by continuing its efforts to educate law enforcement officers about Huntington's disease at the Florida Chiefs of Police Mid-Winter Training Conference and Expo in Orlando, Florida, January 7-10. LEEP (Law Enforcement Education Program Coordinator) Vicki Owen and volunteers Tom Owen and Sharon and Donnie Recore came face to face with hundreds of police officers from all over the state of Florida, providing them with LEEP flash drives and talking to them about how to recognize symptoms of Huntington's and how to appropriately interact with someone who has HD. This event was sponsored by Teva Pharmaceuticals and The Griffin Foundation.



*Left to Right: Vicki Owen, Tom Owen, Sharon Recore, Donnie Recore*



*Left: Sharon Recore and Vicki Owen*

*Above: Vicki and Tom Owen*

# EVENTS 2017

## “Casino Night Out 4 JHD”

Help 4 HD Ambassador Jennifer Nerat hosted “Casino Night Out 4 JHD” at the New Berlin Ale House in New Berlin, Wisconsin, April 22, 2017. The event featured games, raffles, a silent auction, and music, with 100 percent of the net proceeds going to Juvenile Huntington’s disease research. This event raised \$1,952 for the JHD research program at UC Davis.

### Casino Night Out



When: April 22, 2017 at 6:00pm

Where: New Berlin Ale House in New Berlin, WI

Registration Cost: \$21 or \$25 at the door

Come out and join us for a night of fun and excitement to raise awareness and

support for HD/JHD. All net proceeds from this event will go to the Juvenile Huntington’s disease research initiative at University of California, Davis. It is time to put the children first. Come out and support this very important research initiative.

Help  
4HD



Above: Flyer for Casino Night Out 4 HD and attendees play blackjack to win raffle tickets.

Top Right: Sponsor Jennifer Nerat and a volunteer

Center Right: Attendees play craps for raffle tickets.

Bottom Right: Attendees play roulette for raffle tickets.

# EVENTS 2017

## “Drag Queen Bingo”

“Drag Queen Bingo,” organized by LEEP coordinator Vicki Owen, was one of the fun events held this year to raise awareness and funds. Attendees paid to play ten games for the chance to win donated gifts. The event also included a 50/50 raffle. One hundred percent of the net proceeds (\$2,025.73) were divided among LEEP, the Family Relief Fund, and Dr. Juan Sanchez-Ramos’s HD research. The event was held at Hamburger Mary’s in Clearwater, Florida, on July 19.



# EVENTS 2017

## Alabama Association of Chiefs of Police Summer Conference

Help 4 HD International Inc. continued educating law enforcement officers about Huntington's disease at the Alabama Association of Chiefs of Police Summer Conference in Orange Beach, Alabama, July 31-August 3. LEEP (Law Enforcement Education Program Coordinator) Vicki Owen and volunteers Tom Owen and Dawn Hartranft brought education and awareness to hundreds of law enforcement officers from all over the state of Alabama, providing them with LEEP flash drives and talking to them about how to recognize symptoms of Huntington's and how to appropriately interact with someone who has HD. This event was sponsored by Teva Pharmaceuticals and The Griffin Foundation.



*Tom Owen catches a ride from the hotel to the conference hall with one of the law enforcement officers.*



*Attendees visit exhibitors at the Alabama Association of Chiefs of Police Summer Conference.*



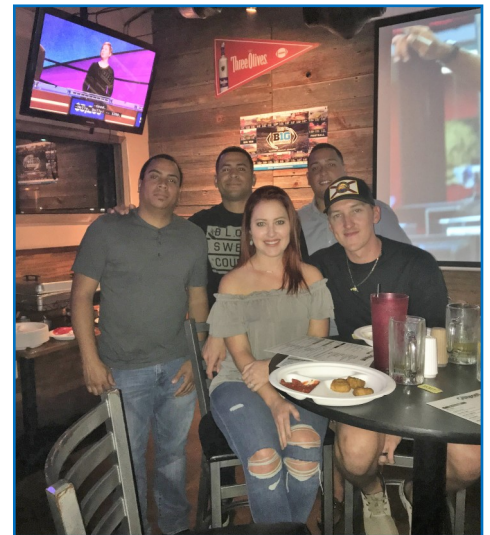
*At the Help 4 HD booth, Tom Owen waits patiently to talk to law enforcement officers about Huntington's disease.*

# EVENTS 2017

## “Cocktails 4 a Cure”

“Cocktails 4 a Cure,” organized by Help 4 HD LEEP Coordinator Vicki Owen, has been a good way to bring together folks who can't attend other events, as it's held in the evening during the week. The event was held at The Outpost Tap House and Tavern in Tampa, Florida, the evening of October 13. It was a networking social geared towards providing business professionals with a fun, engaging, welcoming, and effective networking environment. Admission to the event included two free drinks, a cash bar, appetizers, and live music. A 50/50 raffle was a fun and inexpensive way for us to raise money and awareness and even drew in those who are just regular bar patrons.

One hundred percent of net proceeds (\$825) went to support Help 4 HD's LEEP (Law Enforcement Education Program).



*Left: (L to R) Tom Owen, Katrina Hamel, Jason Chronowitz, Warren Owen, Vicki Owen, Marilyn McCloskey, Donna Owen*

*Above: Members of one of the law enforcement softball teams*



*Left: Marilyn McCloskey and Tom Owen prepare to sell raffle tickets.*

*Above: Tom Owen and Katrina Hamel enjoy hanging out together.*

# EVENTS 2017

## “Strike Out HD”

Help 4 HD International hosted the second annual “Strike Out HD” Softball tournament on October 14 at Woodlawn Field in St. Petersburg, Florida. It made perfect sense with all the relationships that Help 4 HD has built within the law enforcement agencies in Florida that we would host an event that would bring Huntington’s disease families and law enforcement agents together for a fun day at the ball park. Law enforcement agencies and first responder departments came together to raise money for and awareness about Huntington’s disease. Help 4 HD International hung banners that explained the symptoms associated with HD on every field for the agents to be able to read.



This was also a benefit to raise funds for research and relief for families living with Huntington’s and Juvenile Huntington’s disease. All net proceeds from this event (\$3,691.97) went directly to the HD research fund at the University of South Florida and the Help 4 HD Family Relief Fund and Law Enforcement Education Program.

Thank you, Vicki Owen, for working so hard to bring awareness and education about Huntington’s disease to the State of Florida’s law enforcement agents and first responders.



# EVENTS 2017

## Florida Symposium

Help 4 HD's annual symposium was held Saturday, October 21, at the Bay Harbor Hotel in Tampa, Florida. The symposium began with a meet-and-greet Friday night that featured hors d'oeuvres, nonalcoholic beverages, and a cash bar. Medical professionals as well as HD/JHD families showed up Saturday to learn from guest speakers, exhibitors, and from each other.

While registering, participants enjoyed a continental breakfast. The first speaker, Chandler Swope from HDYO (Huntington's Disease Youth Organization), talked about the resources offered by HDYO, then took all youth to a breakout room,

where young people impacted by HD enjoyed their own separate program. Next, Dr. Nikolaus McFarland, University of Florida Center of Excellence, gave an overview of HD symptoms and symptom management. Attendees then moved into parallel sessions.

The first session was a choice between Psychiatric Symptoms and Behavior Changes in HD, led by Terry Tempkin, NP-C, MSN, UC Davis, and Resources for Families Living With Huntington's Disease, led by Janell Strang, MSW, University of South Florida.

During a short break, participants were able to visit exhibitors representing various resources for HD/JHD families and bid on silent auction items, then moved back into parallel sessions.

The second session was a choice between A Research Update from Azevan Pharmaceuticals, presented by Dr. Neal Simon, PhD, and case studies of Managing Behavioral Changes in Huntington's Disease, presented by Terry Tempkin.

Session three featured "The Huntington's Disguise," by Jimmy Pollard, CHDI, a discussion of how the affect of the person with HD often doesn't match what's going on cognitively and emotionally, and why. Alternately, participants could choose to attend the Caregivers HIPE Panel. Fashioned after our popular HIPE (Highly Interactive Participant Education) panels, caregivers Sharon Thomason, Stacey Sargent, and Lauren Holder answered questions presented by the audience about crisis situations that may



Chandler Swope, HDYO



Dr. Nick McFarland, UF



Jimmy Pollard, CHDI



Janell Strang, MSW, USF



Dr. Juan Sanchez-Ramos, USF

# EVENTS 2017

## Florida Symposium (*continued*)

occur with families and individuals living with Huntington's disease. The moderator for the discussion was Terry Tempkin, NP-C, MSN, UC Davis.

During the lunch break, families had an opportunity to meet and talk one-on-one with guest speakers, exhibitors, board members, and other families. Some participants chose to take a leisurely look at and bid on silent auction items.

After lunch, Wendy Erler, MBA, presented a research update from WAVE Pharmaceuticals. Attendees then resumed parallel sessions. The first afternoon session featured a choice between "A Research Update from Kids-HD & Kids-JHD" by Sonia Slevinski, MS, University of Iowa, and an introduction to WeHaveAFace Global HUBS Programs, Projects, and Resources by James Valvano, President/CEO.



Wendy Erler, WAVE Pharmaceuticals



Dr. Neal Simon, Azevon Pharmaceuticals

During a brief break, attendees had another opportunity to visit exhibitors and to bid on silent auction items.

The second afternoon session offered a choice between "A Research Update from the University of South Florida" by Dr. Juan Sanchez-Ramos, MD, PhD, USF and "Law Enforcement Training Overview, Using LEEP (Law Enforcement Education Program)" with Vicki Owen, Help 4 HD.

During the final afternoon break, everyone had their last chance to bid on silent auction items and visit exhibitors as well as writing out questions for the HIPE panel.

The final parallel session featured "A Stem Cell Research Update from UC Davis" by Peter Deng, BS, Doctoral Candidate,



Top: James Valvano, WeHaveAFace  
Middle: Lauren Holder, Stacey Sargent, Sharon Thomason  
Bottom: Terry Tempkin, UC Davis



Katie Jackson, CEO/President, Help 4 HD



Left to Right: Terry Tempkin, Katie Jackson, Vicki Owen, Katrina Hamel, Sharon Thomason, Michael Sabado, Help 4 HD



Above: HD Families enjoy networking

# EVENTS 2017

## Florida Symposium (*continued*)

UC Davis, and a chair yoga session with yoga instructor Lisa Recchione, MA, ERYT-500.

The afternoon's activities concluded with HIPE (Highly Interactive Participant Education) with panelists Dr. Nick McFarland, MD, PhD; UF; Janell Hogan-Strang, MSW, USF; and Terry Tempkin, NP-C, MSN, UC Davis, followed by the announcement of Silent Auction winners.

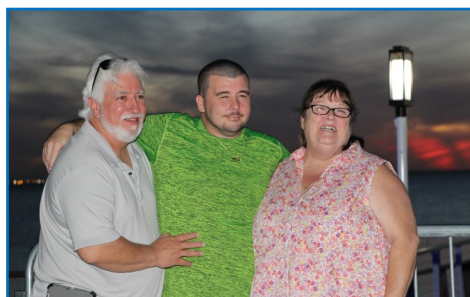
Everyone was invited to attend the evening reception and award ceremony. The reception included hors d'oeuvres, nonalcoholic beverages, dessert, a cash bar, and live music and dancing. At the awards ceremony, the following were recognized: Vicki Owen, Patient Advocate of the Year; Janell Hogan-Strang, Commitment to Support; Jimmy Bunting, HD Person of the Year; Tom Owen, Commitment to Awareness; University of Iowa, Commitment to Care and Research for JHD. Partnering Awards were presented to the following organizations that have partnered with Help 4 HD to help better the lives of our HD/JHD Community: We Have a Face and HDYO.



*Jimmy Bunting, HD Person of the Year*



*Left to Right: Sharon Thomason, James Valvano (Partnership Award), Terry Tempkin, Katie Jackson, Janell Strang (Commitment to Support), Katrina Hamel, Michael Sabado*



*Above: Families enjoy a casual meet-and-greet the night before symposium.*

*Middle Right & Bottom Right: Families enjoy networking with other HD families.*

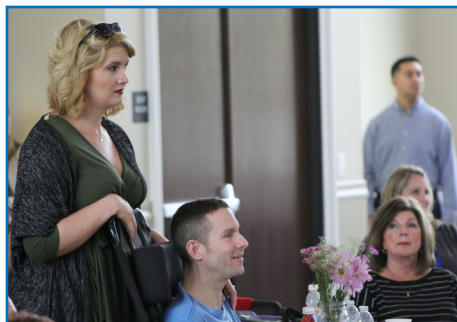


*Left to Right: Sharon Thomason, Terry Tempkin, Katie Jackson, Vicki Owen (Patient Advocate of the Year), Tom Owen (Commitment to Awareness), Michael Sabado, Katrina Hamel*



# PROGRAMS 2017

Help 4 HD International is proud to have introduced or maintained the following programs in 2017:



**HIPE (Highly Interactive Participant Education)** brought an innovative approach to “ask the experts” panels and were the focal point of education days in five cities:

- Sacramento, California
- Kirkland, Washington
- Atlanta, Georgia
- Cedar Rapids, Iowa
- Houston, Texas



## Law Enforcement Education

- Education in a Flash
- FCPA (Florida Chiefs of Police Association)
- AACP (Alabama Association of Chiefs of Police)
- Local law enforcement training
- Flash drives mailed to law enforcement agencies across the U.S.



# PROGRAMS 2017

## HD Family Relief Fund

- Cup of Coffee 4 a Caregiver (Mother's Day and Father's Day)
- Help 4 the Holidays
- Toys 4 the Holidays
- Hurricane relief for Houston, Florida, and Puerto Rico
- Basic year-round relief with critical financial needs

Help 4 HD International is proud to support our  
Huntington's disease and  
Juvenile Huntington's disease community  
this holiday season with:

### *Help 4 the Holidays*

*Help 4 HD International will be offering  
qualifying families \$25/\$50 to go  
towards your holiday meal this  
Thanksgiving and Christmas season. This  
program is a first-come, first-served basis  
for families living in the US. We are run-  
ning this program through our Help 4  
HD International Family Relief Fund.  
To apply for assistance, please go to  
<https://www.research.net/r/help4theholidays>*

Help 4 HD International will be able to help 40 families on a  
first-come, first-served basis.  
Once the 40 gift cards have been committed,  
Help 4 HD will close the project.

*Kids wake up  
And what do they see?  
Holiday toys  
From Help 4 HD!*

*Season's  
Greetings*

Help 4 HD International is offering twenty (20) \$50 gift cards to Toys R Us for families living with HD/JHD in the United States. Funds for this project were raised at the silent auction at the Help 4 HD Florida Symposium held at Wakulla Springs on October 8, 2016. It is our hope that these gift cards will help children of families struggling with HD/JHD to have a happier holiday season. Limit: one gift card per family in the USA.  
Apply online at <https://www.research.net/r/help4hd-toys4kids>

**"Help 4 HD Live!"** on BlogTalkRadio—live weekly programs on a variety of topics including updates on scientific research, discussions with professionals, caregivers, and patients, and information about resources for people living with Huntington's and Juvenile Huntington's disease. Programs are archived and available for listening on BlogTalkRadio and on iTunes.

***The Huntington's Post***—an online newspaper featuring articles on a variety of topics relevant to people living with Huntington's and Juvenile Huntington's disease

**Publications**, including brochures, Help 4 HD Trivia Cards, and a new book, *I Fight for ... Understanding: 31 Days of Coping With Huntington's Disease*

**Support Groups** in California and Florida are affiliated with and supported by Help 4 HD

**Updates of our website**, [www.help4hd.org](http://www.help4hd.org), including the launch of a letter-writing campaign to the FDA, urging them to expedite approval of clinical trials for HD and JHD

**Huntington's Disease and Juvenile Huntington's Disease Awareness Month**—"I Fight for ..." campaign in May

## KEY (Knowledge Empowers You) Webinars

- Drug Access
- Resources

***The Warriors: Fighting the Incurable Juvenile Huntington's Disease***—filming and production of the first-ever documentary about JHD

