

# Help 4 HD International

Educating The World About Huntington's Disease

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Elk Grove, CA 95758

916-698-0462

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

## ANNUAL REPORT 2017: A LOOK BACK AT 2016

### 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 have created programs like Law Enforcement Education Program (LEEP), Help 4 HD Family Relief Fund, "Help 4 HD Live!," *The Huntington's Post*, and many other important programs in order to meet the needs we've identified.

Help 4 HD International is the home of the very first radio show created for the Huntington's disease community. We introduced "Help 4 JHD Live!" to our "Help 4 HD Live!" show schedule in 2016. 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 96,000 all-time listens and over 270 archived episodes available on iTunes and BlogTalkRadio, "Help 4 HD Live!" has been a well-utilized tool for the HD/JHD community to come to in order to get information.

This year, Help 4 HD International attended and exhibited at law enforcement conferences across the nation. 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 are proud to say that many law enforcement agencies are now using these materials to help train their officers about Huntington's disease.

In 2016, Help 4 HD International was able to help many Huntington's and Juvenile Huntington's disease families in need. We provided weighted blankets, medical straps, and gift cards, helped with emergency bills, and also helped families with the holidays this year. We are proud to say that this year, Help 4 HD International helped every family that applied for the holiday help. We also ended the year sending Huntington's disease caregivers a *Holiday Caregiving Tips* magazine that gave them some ideas to help their loved ones and their families through the holidays.

We held events throughout the year that made it possible for Help 4 HD International to donate to Huntington's disease research and care facilities. We held two educational symposia this year where we brought the Huntington's disease community face to face with the experts in the disciplines of neurology, psychiatry, research, and social services, while also allowing the community to network with one another.

We work hard at Help 4 HD International so our future generations do not have to live like our generation and past generations have been forced to do with Huntington's disease. 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 95,000 listeners and the world has free access to over 270 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



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# EVENTS 2016

## Sacramento Symposium

This year, Help 4 HD International hosted the first of two symposia in Sacramento, California, on Saturday, April 9. We featured seven keynote speakers in the disciplines of neurology, psychiatry, and research. Dr. Jan Nolta (UC Davis) began the conference with her “Bench to Bedside” presentation, a talk about PRE-CELL, her stem cell research that she hopes will produce a therapy for HD.

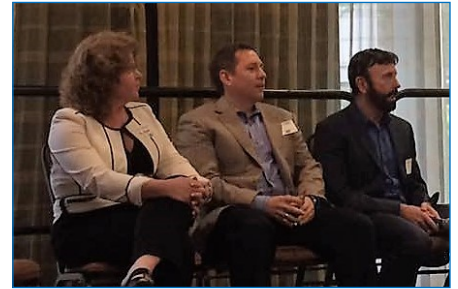
Jimmy Pollard, a popular speaker for CHDI who lives in Lowell, Massachusetts, opened his morning presentation with the theme of “Families Keep Telling Their Stories.” Without those stories, he said, there would be no change. Equally important, according to Pollard, is that families continue to participate in clinical trials.

Following Pollard’s presentation, we heard from a Clinical Trials Update panel: Dr. Victor Abler (Teva Pharmaceuticals), Dr. Ben Cadieux (Raptor Pharmaceuticals), and Dr. Peg Nopoulos (University of Iowa) gave us an update on the clinical trials and studies they are conducting on Huntington’s and Juvenile Huntington’s disease.

Immediately following a buffet lunch, the second part of the day opened with Dr. Vicki Wheelock (UC Davis) speaking about “PRE-CELL: A Pathway Forward and Findings Along the Way.” Dr. Kyle Fink (UC Davis) then spoke about his team’s JHD research, “Gene Therapy in JHD.” Our last speaker was Dr. Peg Nopoulos, who presented “The Neuropsychiatric Disorder,” speaking about psychiatric symptoms associated with Huntington’s disease.

Help 4 HD honored Terry Tempkin for her 18 years of dedication and care to the Huntington’s disease community as an ARNP at the UC Davis Center of Excellence. Judy Roberson then announced the Joseph P. Roberson Foundation’s Huntington’s Disease Person of the Year, Laura Gagnon, who lives in Woodland, California, and is a patient at UC Davis, is active in studies and trials, and is the third person in her family to receive the award. She was a registered nurse for 40 years in maternity and lost her dad and brother to HD.

We finished the day with dessert and Jimmy Pollard’s “Hurry Up and Wait” interactive presentation. Through hands-on presentations and the use of volunteers, Pollard helped the audience understand what it feels like to live with and think with HD



*Clinical Trials Panel: Dr. Peg Nopoulos, Dr. Ben Cadieux, Dr. Victor Abler*



*Dr. Kyle Fink, UC Davis*



During the symposium, participants were able to bid on silent auction items, and 100 percent of all proceeds went to Dr. Kyle Fink’s JHD research at UC Davis.

This was a day filled with patient education. We are thankful to all our sponsors and donors for making this event possible. We would especially like to thank Teva Pharmaceuticals, Raptor Pharmaceuticals, Lundbeck Pharmaceuticals, and Ionis for sponsoring this very important event.

*Left: Approximately 200 participants attended the symposium.*

# EVENTS 2016

## 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 23, 2016. 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 \$8,000 for the JHD research program at UC Davis.



**You are invited to**

**Casino Night Out for JHD**

100% net proceeds of this event will go towards Juvenile Huntington's Disease Research!

**Games, Raffles, Silent Auction**

**Liquor Raffle and Meat Raffle!**

**Saturday, April 23, 2016**  
6pm-11pm

**Doors open at 5:30pm**

**New Berlin Ale House**  
16000 W. Cleveland Ave, New Berlin 53151

**Music and Cash Bar!**

**\$21 Advance Ticket** (register at [www.curejhd.com](http://www.curejhd.com))  
OR  
**\$25 Ticket at the door**

Event ticket includes a raffle ticket and \$500 in Fun Money

Fun money converts into raffle tickets for raffle prizes

\*\*\*Must be 14 years or older\*\*\*

Contact Jennifer Nerat with any questions  
414-208-8986 or [jnerat17@gmail.com](mailto:jnerat17@gmail.com)

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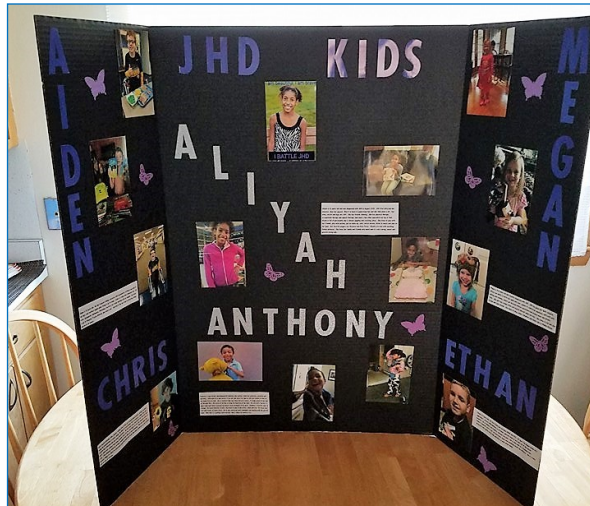
**comedy sportz**

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

Right Top & Center: Honoring kids with JHD and JHD angels

Bottom Right: Attendees play craps for raffle tickets.



# EVENTS 2016

## Jackie's Walk



The first annual Jackie's Walk 4 HD—a fundraising and education event honoring the life and legacy of beautiful Jackie Hamilton who lost a courageous battle with Huntington's disease (HD)—took place on Sunday, May 1, at Glen Island Park, New Rochelle, New York.

Despite the rain, a large crowd turned out for the event hosted by Help 4 HD International and organized by Jackie's daughter, Gabrielle Hamilton. The walk commemorated Jackie's life, as well as benefitting local Huntington's disease patients and families by funding HD research and treatments, providing care and support, and funding HD advocacy efforts.



Highlights of the event included:

- Tribute to the life of Jackie Hamilton with musical accompaniment by trumpeter Richard Fields
- Remarks from HD experts Dr. Andrew Feigin, MD, Director of the Huntington's Disease Center at North Shore University Hospital and Deborah Thorne, LCSW, Social Worker and Clinic Coordinator at Columbia University Medical Center's HD Center of Excellence
- Entertainment, including songs sung by the Rye Neck High School Acapella group
- A short walk around Glen Island Park, with participants walking at their own pace, with several distance options ranging from .2 to 1.5 miles
- A Raffle Extravaganza



The event raised \$16,000, of which \$12,000 was donated directly to Columbia University Medical Center's HD Center of Excellence and Northwell Health: The Movement Disorders Center (formerly North Shore/LIJ), and \$4,000 to Help 4 HD's Family Relief Fund.

### Jackie's Walk 4 HD

Conquering Huntington's disease one step at a time

**Sunday, May 1st**  
10am - 1pm  
**Glen Island Park**  
**New Rochelle, NY**

Short walk; go at your own pace. Fun for the whole family! Entertainment, raffle prizes and more!

**Help make a meaningful impact TODAY and pave the way for a brighter tomorrow. Together, we can conquer HD ... one step at a time. Join Jackie's Walk 4 HD!**

**Register to Walk**  
Eventbrite

**Donate Today**  
FirstGiving

Huntington's disease (HD) is a rare, fatal genetic brain disorder that deteriorates a person's physical and mental abilities. There is **NO** cure. Today, there are approximately 30,000 symptomatic Americans and more than 200,000 at-risk for inheriting HD.

All net proceeds raised will be donated to Columbia University Medical Center HD Center of Excellence, Northwell Health (formerly North Shore/LIJ) and Help 4 HD International Inc. Monies will help fund HD research and treatments, and support patient/family care and advocacy.

Help 4 HD International Inc. is a 501(c)(3) nonprofit public charity. Your generous tax-deductible donation is greatly appreciated. Thank you to our corporate donors for their generous support!

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**Want to Sponsor the event? Call Gaby: 917-686-5576**

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



# EVENTS 2016

## HD/JHD Awareness Month

### LOMPOC HD AWARENESS DAY

This year, Help 4 HD held its second annual HD Awareness Day in May, in Lompoc, California. This free event included children's games, food and drinks, a bounce house, crafts 4 kids, prizes, live music, and a silent auction.

Along with all of the fun activities that were going on during the day, we also had local agencies that offer services to the HD community attend. While everyone was sitting around the park, people from Huntington's disease families were able to meet each other for the first time and bond over similar stories.

Help 4 HD also invited the general public to this event, and, as a result, there were many questions asked and answered, bringing much needed awareness to an underserved community. Because of this event, we were able to provide missing connections in the Central Coast area, including connecting a family member with local mental health services as well as offering support to a woman who had lost her husband and two daughters to Huntington's disease.

This event was created to find members of our HD community, to connect families with HD to local services, and to raise awareness. We succeeded.



*Above: Kids enjoy playing games and winning prizes.*

*Top Right: The band that provided music features drummer Kevin Hamel, who has HD*

*Center Right: Families connect with each other at the Lompoc HD Awareness Day*

*Bottom Right: The silent auction raised \$2,668 to go to Caring 4 HD expenses.*

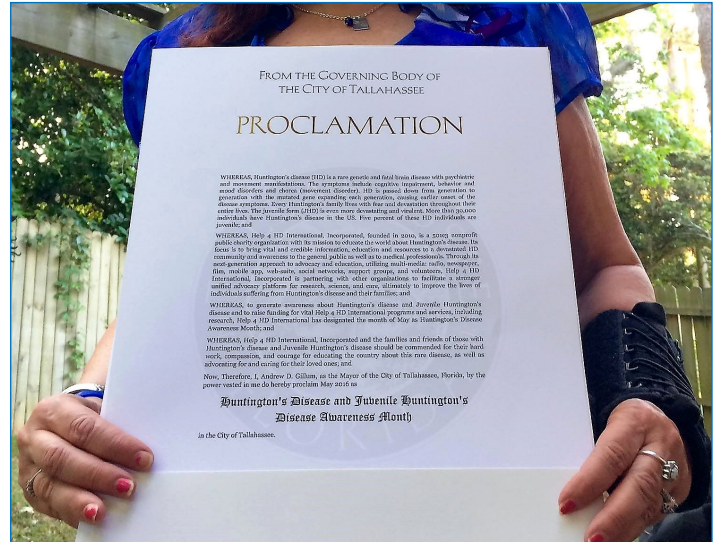
# EVENTS 2016

## HD/JHD Awareness Month

### TALLAHASSEE HD/JHD AWARENESS MONTH

Mayor Andrew Gillum kicked off HD Awareness Month at the City Commission meeting in Tallahassee, Florida, on May 10, issuing a Proclamation declaring May as Huntington's and Juvenile Huntington's Disease Awareness Month. Commissioner Gil Ziffer presented the proclamation to members of the Tallahassee Help 4 HD Support Group. Afterward, Sharon Thomason, facilitator of the support group, spoke to the approximately 100 people assembled at the meeting about Huntington's and Juvenile Huntington's disease.

HD Awareness Month continued with the support group sponsoring a free viewing of the documentary "The Huntington's Disease Project: Removing the Mask" at John Wesley United Methodist Church on May 21.



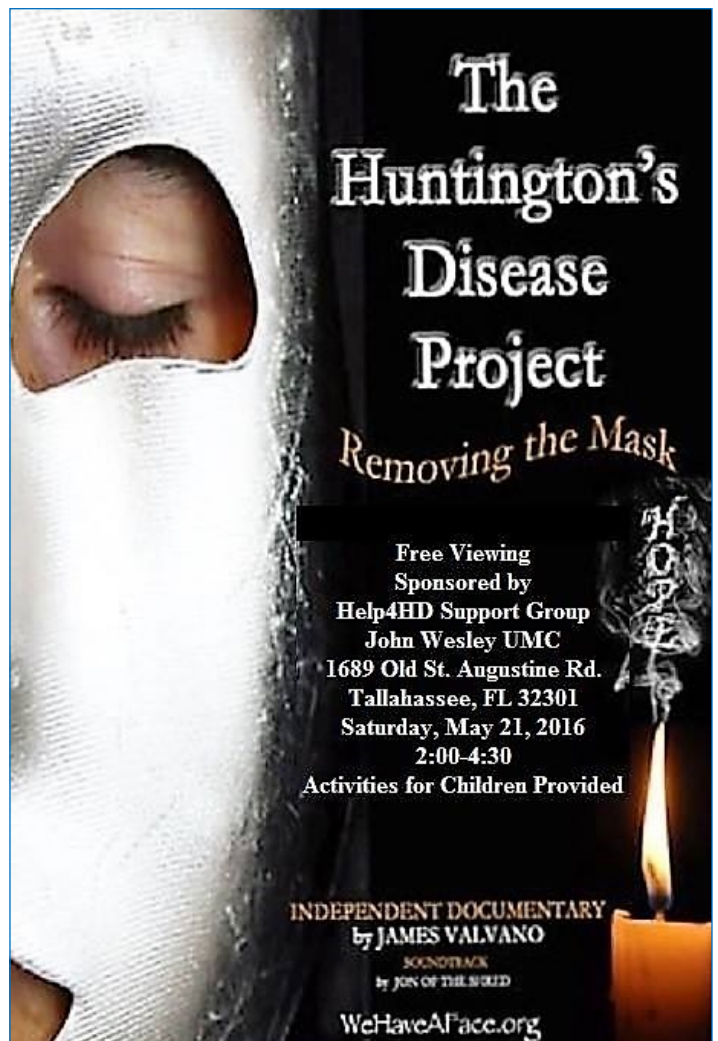
Mayor Andrew Gillum proclaims May as Huntington's Disease and Juvenile Huntington's Disease Awareness Month in Tallahassee, Florida.



City Commissioner Gil Ziffer reads the Proclamation declaring May as Huntington's and Juvenile Huntington's Disease Awareness Month in Tallahassee.



Sharon Thomason accepts the Proclamation and talks about HD and JHD.



# EVENTS 2016

## Cocktails 4 a Cure

Cocktails for a Cure, organized by Help 4 HD ambassador 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 August 12, in Tampa, Florida. This year's event will be held either in March or April at the Outpost, which has hosted two of these for us in the past. They have been very supportive of the Huntington's disease community and will continue to be so as we go forward.

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.

Net proceeds of \$825 went to the University of South Florida to support Dr. Juan Sanchez-Ramos's HD research.



## Live in Hope

Help 4 HD International hosted a "Live in Hope" benefit in Council Bluffs, Iowa, on September 24, in honor of Denise Hudgell's 11-year-old son, Aidan Smith, who has been battling Juvenile Huntington's disease and epilepsy since the age of four.

The benefit included a volleyball tournament, dinner, raffles, silent auction baskets, and casino night. The event concluded with entertainment by a local band. There were 250 people who attended throughout the day.



stitute for Regenerative Medicine at UC Davis in California, where Dr. Nolta's and Dr. Kyle Fink's team is working on a cure for JHD.

# EVENTS 2016

## Florida Symposium

Help 4 HD's second symposium of the year was held Saturday, October 8, at The Lodge at Wakulla Springs, outside Tallahassee, Florida. The first symposium to be held outside California began with a meet-and-greet Friday night that featured hors d'oeuvres, a dessert bar, and live music. Though uninvited guest Hurricane Matthew tried to spoil the fun, about 120 people, including medical professionals as well as HD/JHD families, still showed up Saturday to learn from guest speakers, exhibitors, and from each other.

While registering, participants enjoyed a continental breakfast. The first speaker, Dr. Jan Nolte (UC

Davis Institute of Regenerative Cures), spoke about her work with stem cell research to find a cure for HD. The next speaker, Dr. Victor Abler, from Teva Pharmaceuticals, shared the latest update on his company's drug development for treatment of HD. 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 into breakout sessions.

One session, led by Sonia Slevinski, focused on the Kids-HD and Kids-JHD research being conducted at the University of Iowa, where she is the lab research manager. The second session, led by Katie Farmer, genetic counselor at Tallahassee Memorial Regional Hospital, focused on issues surrounding genetic testing. The third session, led by Katie Jackson and Katrina Hamel, president and vice president of Help 4 HD, answered questions about and generated ideas for educating law enforcement about HD and JHD.

During the lunch break, families had an opportunity to meet and talk one-on-one with guest speakers, exhibitors, board members, and other families. Participants were given vouchers for tickets to go on the Jungle Cruise, one of Wakulla Springs State Park's major attractions, and many participants decided to take the cruise and see alligators and other wildlife in their natural habitat. Some participants chose to take a leisurely look at and bid on nearly 50 silent auction items.

After lunch, Dr. Juan Sanchez-Ramos (University of South Florida, Tampa) kicked off the afternoon session with a talk about his research into direct delivery of gene-



*Dr. Jan Nolte, UC Davis*



*Dr. Victor Abler, Teva*



*Kids-HD and Kids-JHD giveaways from University of Iowa*



*Dr. Juan Sanchez-Ramos, USF*

# EVENTS 2016

## Florida Symposium (*continued*)

silencing molecules into the brain via a nasal spray. Next, Dr. Nikolaus McFarland (University of Florida, Gainesville) spoke about the UF Center of Excellence and talked about his research into how RAN proteins may cause and/or affect the development of HD. Next up was popular speaker Jimmy Pollard (CHDI) who warmed up the audience with some quick trivia about Wakulla Springs, then did a presentation on “The Huntington’s Disguise”—how the affect of the person with HD often doesn’t match what’s going on cognitively and emotionally, and why.

During the afternoon break, raffle tickets for a stained glass “Hope” were sold, and everyone had their last chance to bid on silent auction items.

The final speakers of the information-packed day were Dr. Herbert Ward (UF) and Dr. Catherine Passariello (GeneSight). Dr. Ward spoke about the psychiatric considerations that are often not recognized nor spoken about with HD and how they may be treated. Dr. Passariello shared information about pharmacogenetic testing that enables doctors to test which psychiatric medications might be most appropriate for individual patients, based on their genetic makeup.

The day closed with a recognition of and tokens of remembrance for mothers who have lost their children to JHD and recognition and awards for Florida’s LEEP (Law Enforcement Education Program) team: Vicki and Tom Owen, Sharon and Donnie Recore, Deborah and Jimmy Bunting, and Marcia McCall. Saturday evening brought time for those who were staying overnight to sit back, relax, and reflect on the day’s activities and information. We celebrated Vicki Owen’s birthday with a cake and a candy bar and enjoyed live music. Net proceeds from the silent auction and raffle totaling \$2250 were donated to Dr. Jan Nolte’s research lab at UC Davis and to Help 4 HD’s holiday Toys 4 Kids program.



Terry Sargent, Jimmy Pollard,  
Stacey Sargent



Dr. Herbert Ward, UF



Above, Top Left, Middle Left: HD/JHD families network with one another.



Katie Jackson and Katrina Hamel present Dr. Jan Nolte with a check from Denise Hudgell’s Live in Hope event.



Executive Board Michael Sabado, Katie Jackson, Katrina Hamel, and Sharon Thomason



Nurses and social workers attended and earned CEUs



# EVENTS 2016

## A Night Out 4 HD

This year, Help 4 HD International hosted the first Night Out 4 HD on October 27, to support the Huntington's disease clinic at UC Davis. This was a wine and food pairing event. We had live music, a silent auction, and a raffle. Individuals that attended the event got to taste food from local restaurants as well as pairing that food with wine and micro brews. We also had our "How Sweet It Would Be to Cure HD" dessert table. There was a large table filled with a variety of desserts that could be paired with dessert wines. We had a packed house at this event, filled with people who came out to support the Huntington's disease clinic at UC Davis.

We opened the presentation part of this event with a video of the clinic. Then Judy Roberson took the microphone to talk about how the clinic started and how much the clinic means to the 600 families that it serves. After Judy finished, Dr. Vicki Wheelock presented Help 4 HD International's lifetime achievement awarded to Judy Roberson.

This was an amazing event that raised \$8,164 for the clinic as well as bringing Huntington's disease awareness to the area.



# EVENTS 2016

## Strike Out HD

Help 4 HD International hosted the first annual Strike Out HD Softball tournament on October 30 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 event raised \$4,200 that was divided among Huntington's disease research at the University of South Florida, Help 4 HD's LEED (Law Enforcement Education Program), and Help 4 HD's Family Relief Fund.

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.



**Help 4 HD International Inc.**  
Educating The World About Huntington's Disease

Huntington's disease is a genetic, neurodegenerative, terminal brain disease that affects males and females, all ages, and all races.

Some symptoms of Huntington's disease include:

- Chorea (involuntary movements)
- Slurred speech
- Tremors
- Dystonia
- Rigidity
- Choking
- Problems with gait and balance
- Suicidal thoughts and action
- Depression
- Anxiety
- Psychosis
- Dementia
- Apathy
- Agitation
- Perseveration
- Loss of ability to walk, sit up, talk, and swallow

People with Huntington's disease may also have delayed response due to cognitive impairment.

To learn more please go to [www.help4hd.org](http://www.help4hd.org)



# PROGRAMS 2016

Help 4 HD International is proud to have introduced or maintained the following programs in 2016:

## Law Enforcement Education

- Education in a Flash
- IACP (International Association of Chiefs of Police)
- FCPA (Florida Chiefs of Police Association)
- Local law enforcement training

## HD Family Relief Fund

- Help 4 the Holidays
- Toys 4 the Holidays
- Caregivers Christmas Guides
- Basic year-round relief with financial needs

“Help 4 HD Live!” on BlogTalk Radio—weekly programs, including

- Celebrating the Advocates
- Clinical trial updates

“Help 4 JHD Live!”

*The Huntington’s Post*—an online newspaper featuring 13 new articles on a variety of topics, including advocacy, death with dignity, first-ever JHD Walk, Sacramento Symposium 2016, personal columns, mental illness with HD, pharmacogenetic testing, guidelines for genetic testing, our first IACP Conference, a history of HD, and a profile of JHD honoree Cameron Brown

Caring 4 HD—a thrift shop and resource center in Lompoc, California

Publications, including two new ones

- HD Trivia
- Safe Proofing Your House

## Support Groups

JHD Research Initiative—a grand total of \$22,145 donated

Research 4 HD—a grand total of \$19,100 that went out to care and research from Jackie’s Walk, A Night Out 4 HD, and Cocktails 4 a Cure

Launch of our new website, [www.help4hd.org](http://www.help4hd.org)