

## What is Huntington's Disease?

Huntington's disease (HD) is a hereditary neuro-degenerative brain disease. Every child of an individual with HD has a 50/50 chance of inheriting the same fate. HD is a trinucleotide repeat disorder where the mutated gene causes unstable CAG (cytosine-adenine-guanine) expansion.

Every individual has a CAG repeat, but the normal range is 10-26. An individual with a CAG repeat >38 will have Huntington's disease at some time in his/her lifetime. The gene was discovered in 1993, and a diagnostic genetic blood test was developed.

The juvenile form of Huntington's disease (JHD) is more progressive and virulent. Children with JHD represent about 5% of all HD cases and are diagnosed with family history, a CAG of >60 repeats and diagnosed before the age of 20. Symptoms include: uncontrolled movements called chorea, decline in scholastics, memory loss, itching, psychiatric behaviors, seizures, dystonia, loss of balance, and tremors to name a few.

Individuals with HD and JHD eventually lose their ability to take care of their own needs and become completely dependent on caregivers for everything. Care of HD individuals is extremely challenging and requires coordination of many disciplines. Mortality typically ranges between 10-25 years for HD and less for JHD, about 10 years upon onset.

### Contact us or donate to:

**Help 4 HD International**  
5050 Laguna Blvd. 112 543  
Elk Grove, CA 95758

**Katie@help4hd.org**

**Visit us on the web:**  
**www.Help4HD.org**



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# WHO IS Help 4HD?

**HELP 4 HD International**

**Help4HD.org**

**Help 4 JHD**

**HD Family Relief Fund**

**Help 4 HD Live!**

**Help 4 HD TV**

**The Huntington's Post**

**First Responders HD Education**

**Law Enforcement HD Education**

**Support Groups**



# Who is Help 4 HD International?



**Help 4 HD is a grassroots patient advocacy organization** that utilizes multimedia communications and social media to propel its education and advocacy mission. Help 4 HD events, conferences,

publications, and support groups inform and inspire the Huntington's disease community.

## **Help 4 HD Live!:**

This podcast goes live every Wednesday. Look for episodes on Help 4 HD Live! at [www.help4hd.org](http://www.help4hd.org) under the Help 4 HD Live! tab. You can check out over 500 archived episodes on Spotify, iTunes, and iHeart Radio. This is the first podcast ever created for the HD/JHD community.

## **Help 4 HD Support Groups:**

Please contact us through our website at [www.help4hd.org](http://www.help4hd.org) "contact us" page to learn about our in-person or virtual support groups.

## **Help 4 HD TV:**

This is a once-a-week TV show where we interview families and professionals on content pertaining to HD/JHD. Check it out at Help4HDTV on YouTube.

## **Help 4 HD Family Relief Fund:**

This program helps Huntington's disease and Juvenile Huntington's disease families with immediate emergency assistance and special holiday programs. We have dedicated thousands of dollars to this program and have helped many families in need.

## **Law Enforcement Education Program (LEEP):**

Help 4 HD International's LEEP program has helped educate thousands of law enforcement agents and first responders about Huntington's disease.

## Commitment to serve

### **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**

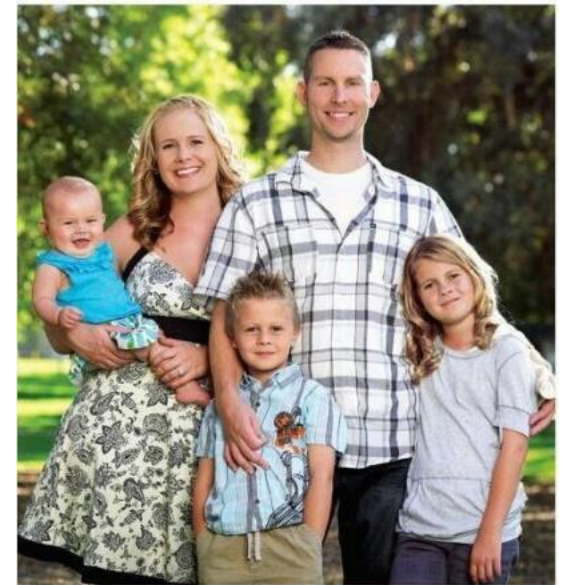
Help 4 HD's goal is to continue establishing strong roots in the underserved communities and to seek out new underserved areas to educate, help, and serve.

### **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.

Contact: Katie Jackson, President/CEO  
Help 4 HD International Inc.  
[katie@help4hd.org](mailto:katie@help4hd.org)  
Office: 916-698-0462

*Publication made possible by*



*President, Katie Jackson, husband Michael and their amazing children. Mike was diagnosed in 2007 and passed away in 2019. Their children have a 50/50 chance of inheriting the same fate.*

## Family First!

### **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.

*"Help 4 HD International has been able to reach a portion of the Huntington's community that no one else has."--Dr. LaVonne Goodman, Seattle, WA*

### **HELP 4 HD's SUPER SIX**

1. Communications
2. Education
3. Events & Conferences
4. Fundraising Initiatives
5. Patient Advocacy
6. Support Services