

After Diagnosis

Because JHD affects cognitive ability, many young people need special accommodations in school. Since JHD is considered a disability, children are eligible for an IEP (Individual Education Plan) that prescribes special accommodations and modifications that may need to be made. The IEP is renewed at least annually, though it can be revised any time changes occur that need to be addressed. An IEP may include special equipment, such as a special chair or an iPad, as well as therapists and an aide assigned specifically to the child.

Children with JHD are eligible for SSDI (Social Security Disability Income) under the Compassionate Allowances and may also be eligible for additional SSDI as the disabled child of a disabled adult if they are unmarried, age 18 or older, and have a disability that started before age 22.



Randy receives SSDI under his own work record as well as his dad's because he was diagnosed at age 21. His dad was diagnosed with HD at age 35 and died from HD at the age of 52.



Hope for the Future

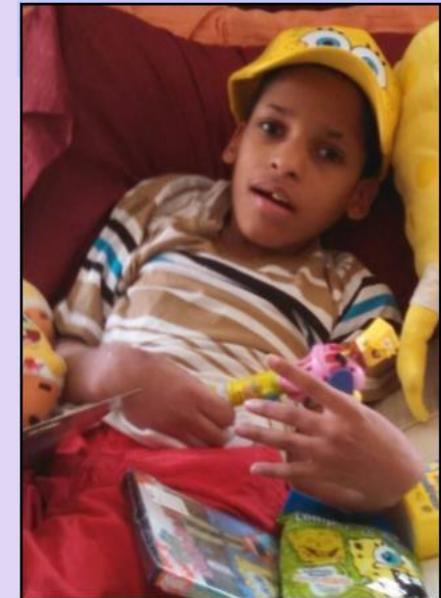
Dr. Jan Nolta's lab at UC Davis is working toward the first clinical trials ever for JHD. The research program is headed by Dr. Kyle Fink, who hopes to develop a cure for JHD using gene editing technology. Help4JHD held the inaugural JHD walk in June 2015 to raise money to support this research. More information can be found at: www.help4hd.org/help-4-jhd/

Help4HD-International.org has also partnered with Dr. Peg Nopoulos, University of Iowa, on the Kids-HD and Kids-JHD programs. Currently, Dr. Nopoulos' Kids-HD and Kids-JHD study is the largest study for Juvenile Huntington's disease and is supported by funding from CHDI and the University of Iowa.



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Understanding Juvenile Huntington's Disease



*Cameron Brown, age 13
2015 JHD Walk Honoree*

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What Is JHD?

Huntington's disease is an autosomal, genetic, neurodegenerative disease that is passed down from one generation to the next. There is no treatment and no cure. It is always fatal.



Cory Sargent, 21, was diagnosed with JHD at age 15 after being misdiagnosed with Cerebral Palsy at age 10. His mom, Stacey, is a strong advocate for JHD.

Individuals who have tested positive for HD suffer from cognitive impairment, psychiatric and behavioral symptoms, and movement disorders.

When the onset of symptoms occurs in children, teens, and young adults, the disease is referred to as Juvenile Huntington's disease (JHD), and in this

form, it is particularly cruel and progresses faster than the adult onset of HD.

JHD is usually, but not always, inherited from the father. Whether inherited from the father or the mother, every child of an affected parent has a 50 percent chance of inheriting HD. About 10 percent of those who test positive for HD have JHD.

Everyone is born with the huntingtin gene, but those who develop HD and JHD have an abnormally high number of CAG repeats in the gene. The CAG repeats create a toxic protein that slowly kills brain cells. HD/JHD occurs in both males and females

and in all ethnic groups. It has been diagnosed as early as two years old.

Symptoms of JHD

Symptoms of JHD can be different from those of HD. Rather than exhibiting the involuntary, writhing movements referred to as *chorea*, often associated with HD, kids with JHD (particularly those younger than 10) often experience *dystonia*, a stiffness and rigidity of the body. Teens may develop involuntary fidgety movements and seem more likely to develop psychiatric and behavioral symptoms. Other symptoms frequently seen in JHD include:

- ~ Decline in mental ability
- ~ Walking on tiptoes
- ~ Development of clumsiness and loss of balance
- ~ Seizures
- ~ Neuropathy, including unexplained itching
- ~ Changes in behavior
- ~ Swallowing and speech problems
- ~ Loss of ability to run, kick or throw a ball, write
- ~ Difficulty sleeping
- ~ Drooling
- ~ Depression
- ~ Impulsivity
- ~ Aggression
- ~ Hypersexuality
- ~ Obsessive, compulsive behavior



Aidan Smith, 10, was diagnosed with JHD at age 6, but began showing symptoms at age 4. Itching frequently keeps him and his mom, Denise Hudgell, awake at night.

Testing for JHD

A simple genetic blood test will determine whether a person has HD/JHD; however, doctors are often reluctant to test anyone younger than 18, even when there are symptoms and a strong family history of the disease present. Because there is no effective treatment and no cure for JHD, doctors usually rule out all other possible causes of symptoms rather than performing the genetic test.



Lizzie Gonzalez, 17, was diagnosed with JHD at age 10. Her symptoms, which began at the age of 5, resulted in her school classifying her as mentally retarded.

In children with JHD, this often results in years of misdiagnosis. Many children with JHD initially receive diagnoses of ADHD (attention deficit hyperactivity disorder), ODD (oppositional defiance disorder), developmental delays, and an assortment of other neurological and psychiatric disorders.

Diagnosis of JHD can take years. Doctors usually begin by taking

a medical history, a family history, and a developmental history. Then they perform a neurological exam and a neuropsychiatric assessment that serve as a baseline for future comparison. They may also order brain imaging and other tests to rule out other conditions that may be causing the symptoms. Once diagnosed, a treatment team may include a neurologist, a psychiatrist, occupational, physical, and speech therapists, a social worker, and a dietician, as well as the pediatrician.