

***After Diagnosis***

**Understanding**

**Juvenile**

**Huntington ’s**

**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 ac-**

**commodations 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 spe-**

**cial chair or an iPad, as well as**

**therapists and an aide assigned**

**specifically to the child.**

**Disease**

***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 technolo-

gy. Help4JHD held the inaugural JHD walk in June

2015 to raise money to support this research. More

information can be found at: www.help4jhd.org

**Children with JHD are eligible**

**for SSDI (Social Security Disabil-**

**ity Income) under the Compas-**

**sionate 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.**

Help4HD-International.org has also partnered with

Dr. Peg Nopoulos, University of Iowa, on the Kids-

HD and Kids-JHD programs. Currently, Dr. Nopou-

los’ Kids-HD and Kids-JHD study is the largest

study for Juvenile Huntington’s disease and is sup-

ported by funding from CHDI and the University of

Iowa. More information can be found at:

***CameronBrown,age13***

***2015JHDWalkHonoree***

www.help4hdinternational.org/Help4JHD.html

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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.

**Sharon M. Thomason**

**Help 4 HD International**

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***Testing for JHD***

***What Is JHD?***

and in all ethnic groups. It has been diagnosed as

early as two years old.

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 perform-

ing the genetic test.

Huntington’s disease is an autosomal, ge-

netic, neurodegenerative disease that is

passed down from one generation to the

next. There is no treatment and no cure. It

is always fatal.

***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:

Individuals who

have tested positive

for HD suffer from

cognitive impair-

ment, psychiatric

and behavioral

symptoms, and

movement disor-

ders.

In children with JHD,

this often results in

years of misdiagnosis.

Many children with

JHD initially receive

diagnoses of ADHD

(attention deficit hy-

peractivity disorder),

ODD (oppositional

defiance disorder),

Decline in mental ability

Walking on tiptoes

When the onset of

Development of clumsi-

ness and loss of balance

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.

symptoms occurs in

children, teens, and

young adults, the

disease is referred

to as Juvenile Hun-

tington’s disease

Seizures

Neuropathy, including

unexplained itching

developmental delays,

and an assortment of

Lizzie Gonzalez,17,

was diagnosed with

Changes in behavior

Swallowing and speech

problems

JHD at age 10. Her

symptoms, which

began at the age of 5,

other neurological and

psychiatric disorders.

(JHD), and in this

form, it is particularly cruel and progresses

faster than the adult onset of HD.

resulted in her school Diagnosis of JHD can

classifying her as

mentally retarded.

take years. Doctors

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.

Loss of ability to run, kick

Aidan Smith, 10, was

usually begin by tak-

ing a medical history, a family history, and

a developmental history. Then they per-

form a neurological exam and a neuropsy-

chiatric assessment that serve as a base-

line 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 treat-

ment team may include a neurologist, a

psychiatrist, occupational, physical, and

speech therapists, a social worker, and a

dietician, as well as the pediatrician.

or throw a ball, write

Difficulty sleeping

Drooling

diagnosed with JHD at

age 6, but began show-

ing symptoms at age 4.

Itching frequently keeps

him and his mom, Den-

ise Hudgell, awake at

night.

Depression

Everyone is born with the huntingin gene,

but those who develop HD and JHD have

an abnormally high number of CAG re-

peats in the gene. The CAG repeats create

a toxic protein that slowly kills brain cells.

HD/JHD occurs in both males and females

Impulsivity

Aggression

Hypersexuality

Obsessive, compulsive behavior

