



# Juvenile Huntington's Disease and the School Experience:

*Education and the Child Affected by Juvenile Onset HD*



Huntington's Disease  
Society of America





# Juvenile Huntington's Disease and the School Experience:

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*Education and the Child Affected by Juvenile Onset HD*

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## **A Message from HDSA**

Dear Reader:

If you are using these materials, it is because you have a child affected by juvenile onset HD in your home, classroom or school system. Welcome. We hope that these new resources, which were made possible by a generous grant from the American Legion Child Welfare Foundation, will provide you with the information you need as you work toward helping the child affected by juvenile onset HD make the most of his academic experience.

Approximately 10% of the US Huntington's Disease population is affected by juvenile onset HD which strikes very young children, as early as the age of 2 and before the age of 18-20 (hence the name juvenile HD). The disease course for JHD is more severe and accelerates at a faster pace than adult onset HD and thus these children become symptomatic before they have the opportunity to reach adulthood.

Research has demonstrated that children maintain independence and feel less isolated and "different" when they are able to remain in school while battling a long term or fatal disease. Friends are important to children and making provisions and accommodations that allow the student with JHD to maintain friendships is invaluable while teaching classmates tolerance and acceptance to those who may be "different".

Yet the vast majority of school systems and educators have no knowledge or experience with HD. Classmates do not understand that HD is a disease and the symptoms being exhibited by their friend or classmate are the result of brain cells dying. They only recognize that their friend is acting differently; may walk with a lurch; suddenly stiffen; strike out or be increasingly hard to understand. School plays a vital role in teaching children to accept differences and embrace diversity.

The purpose of this project is to create educational materials for school administrators, teachers, aides, classmates and parents so each of you can help the child with JHD have a fulfilling school experience. We hope that these materials will give you a better understanding of the inevitable changes that will occur and thus allow you to make the accommodations that are needed to afford the child with HD the best chance to remain in school surrounded by their peers and friends.

We also hope that these materials will help to teach children the importance of retaining friendships with these students so they can continue to be an active and vital part of the school community.

Though the child with JHD may face a decrease in their abilities, both mental and physical, over time, and sometimes, even within the course of a semester, schools can accommodate and adapt to meet the new challenges faced by these "special needs" children.

Please let us know how these resources have helped you to develop a fulfilling school experience for your child affected by juvenile onset HD.



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# Disclaimer

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- This presentation was created to increase the understanding of JHD in the educational professionals who are involved in the schooling of a student with JHD.
- It contains “best practices” as suggested by people in the field who have worked successfully with JHD students.
- Nothing in this presentation claims to diagnose any condition, prescribe any specific treatment, or to take the place of consultation with qualified professionals.

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# **Juvenile Huntington's Disease in the School: Understanding JHD**

## **Questions and Answers for School Staff and Administrators**

# Special Thanks

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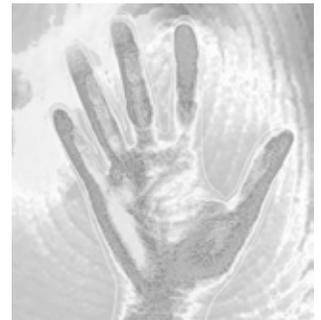
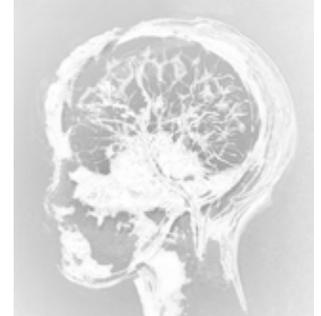


**HDSA wishes to thank  
the American Legion  
Child Welfare Foundation  
for their continued  
support of the HDSA's  
Juvenile HD Program.**

# What is JHD and how do you get it?

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- Juvenile Huntington's Disease (JHD) is a hereditary brain disease.
- Over time, this rare disorder causes increasingly severe disabling symptoms.
- No one can "get" JHD.
  - *It is an inherited genetic disease.*
  - *Only a person who is born with the defective gene can ever get the illness.*
  - *It is not contagious.*



# What does JHD do?

- JHD causes the progressive loss of nerve cells in the brain.
- This affects:
  - *Movement*
  - *Cognition*
  - *Emotions and Behavior*



# Is there a cure for JHD?

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- There are currently no treatments that slow or stop the disease, although there are medications which may help with some of the symptoms.



# JHD in school

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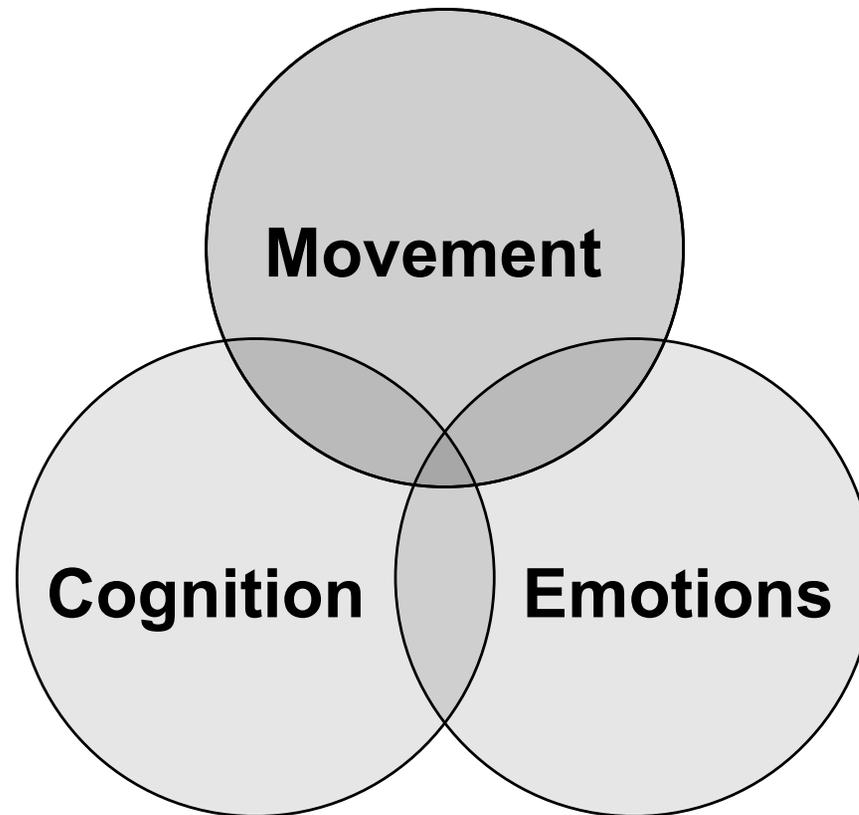
- A diagnosis of JHD does not prevent a student from having a successful educational experience.
- However, a student with JHD will need a wide range of assistance to thrive in school.



# **The Connected Effects of JHD**

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- The multiple disabilities of JHD combine to affect the entire person.

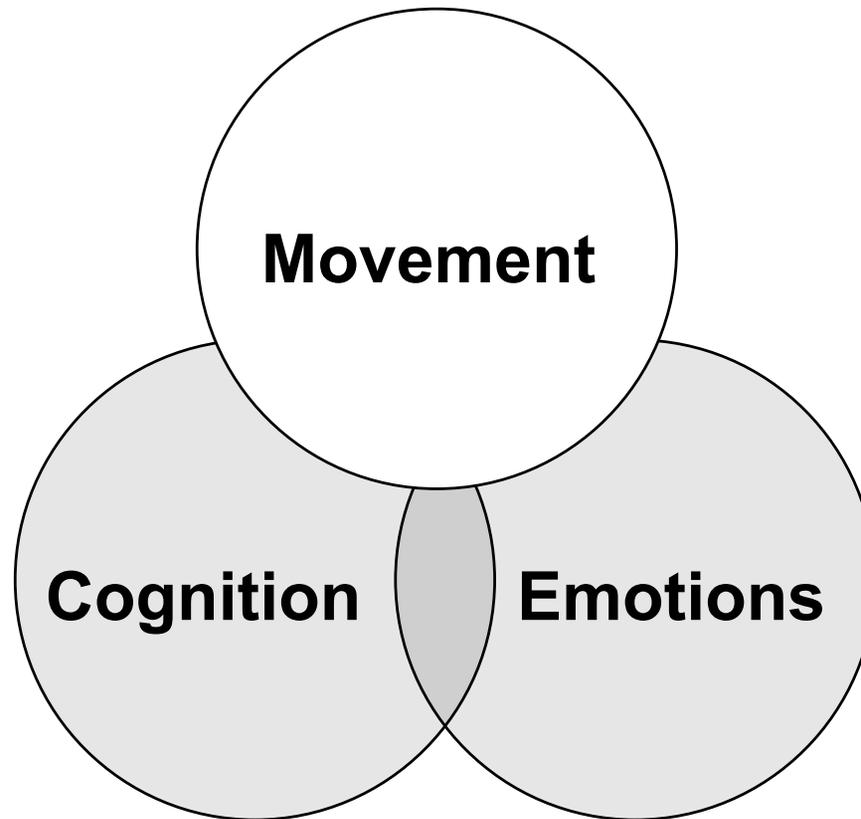


*Diagram based on the work of Jane Paulsen, Ph.D. as found in "Understanding Behavior in Huntington's Disease".*

# The Connected Effects of JHD

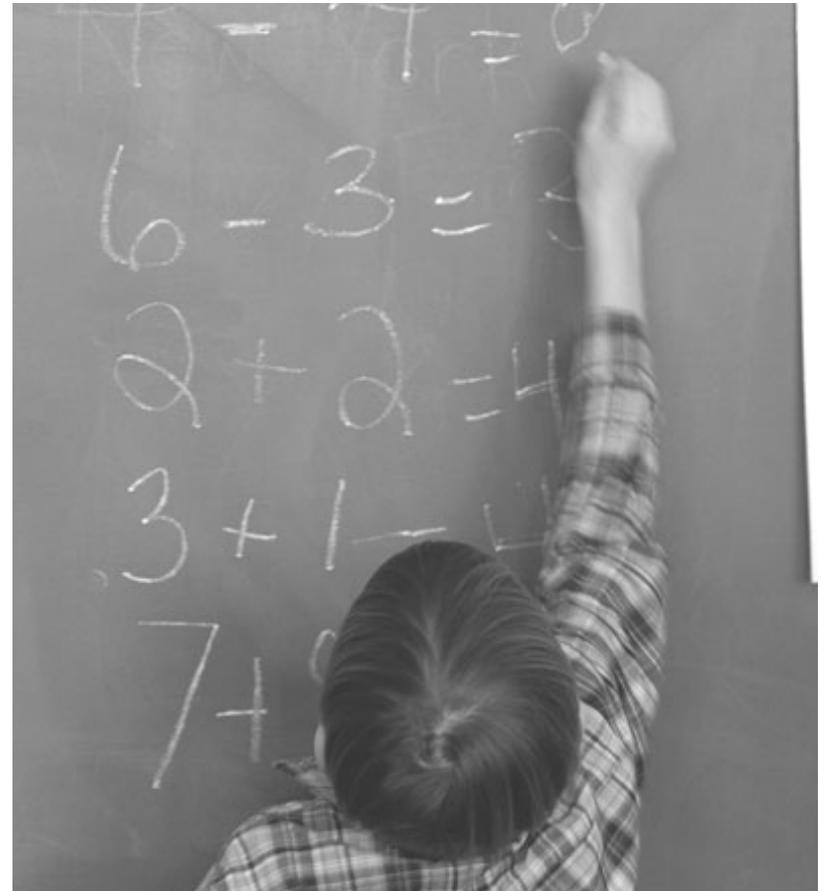
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## 1. Movement disorders



# Movement

- Movement disorders caused by JHD may include:
  - *Abnormal balance*
  - *Loss of muscle control*
  - *Rigidity*
  - *Spasticity*



# Movement

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- JHD causes changes in motor skills and coordination.
- Over time, a young person with JHD will lose skill and ability in:
  - *Walking and running*
  - *Playing sports*
  - *Writing and keyboarding*
  - *Using tools and utensils*



# Movement

- JHD also reduces oral motor control thus causing:
  - *Indistinct speech*
  - *Drooling*
  - *Choking and difficulty eating*



# Movement

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- A student can overcome the movement disorders caused by JHD and continue their education with help from the school in the areas of:
  - *Physical Therapy*
  - *Occupational Therapy*
  - *Speech Therapy*
  - *Assistive Devices*
  - *Adaptive Physical Education classes*
- More information is included in the “Best Practices” section of the disc.



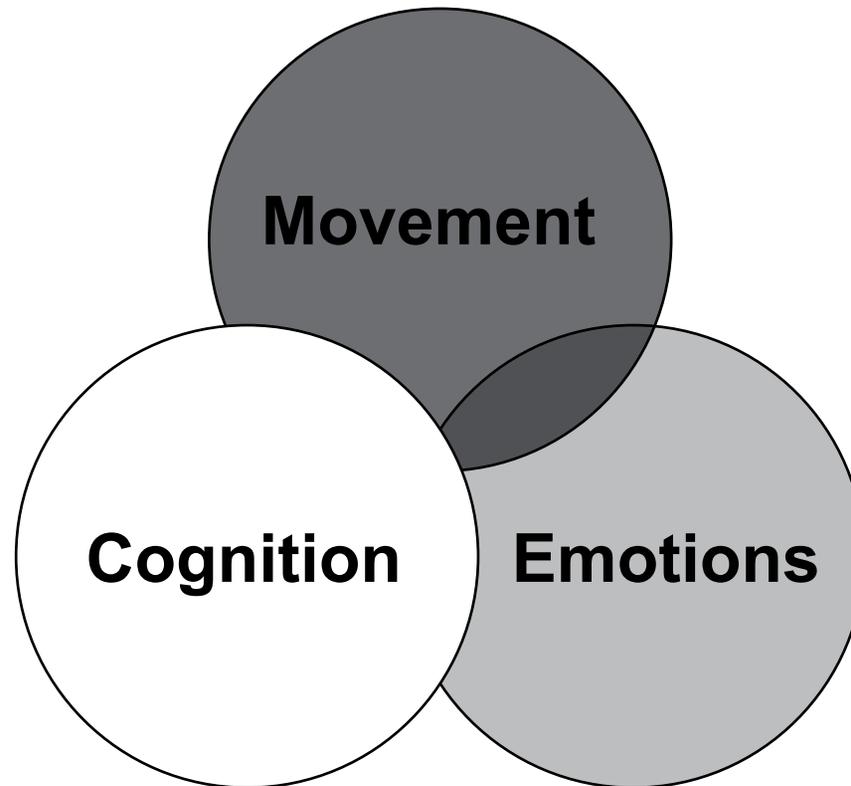
**“Early detection and intervention will help the child maintain the ability to function and communicate.”**

*- Physical therapist*

# The Connected Effects of JHD

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## 1. Cognitive disorders



# How does JHD affect cognition?

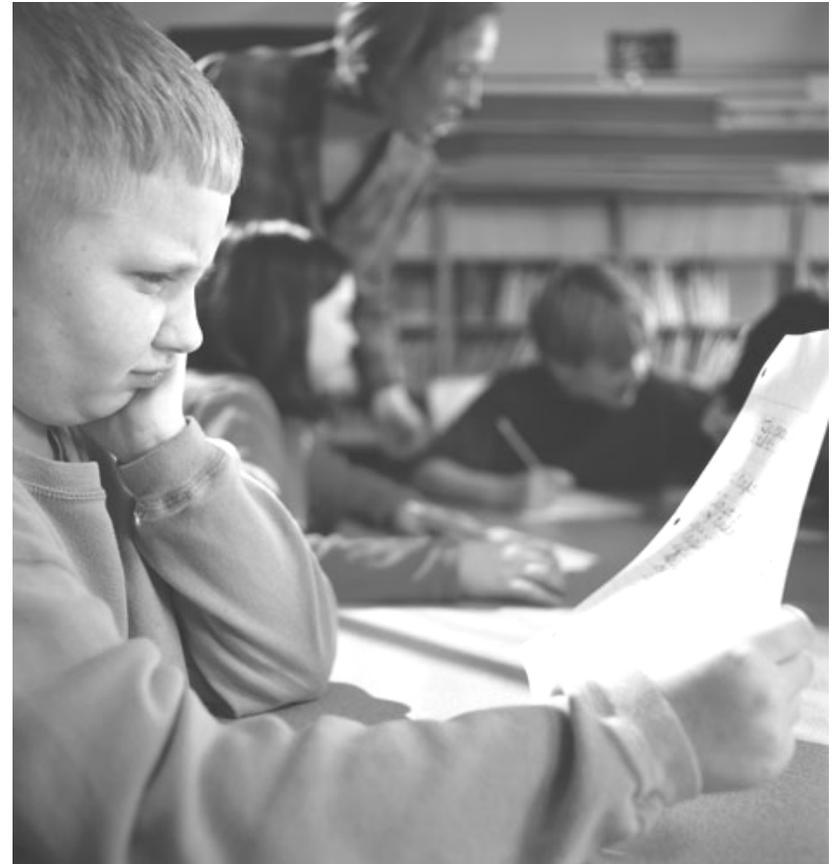
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- JHD causes the progressive loss of nerve cells in the brain.
- This loss affects the ability of the brain to understand, organize and retain information.



# Cognition

- Changes in cognition may be an initial indicator of JHD.
- Symptoms may include:
  - *Lack of attention/concentration*
  - *Loss of previously learned skills*
  - *Declining ability to learn new material*



# Cognition

- JHD also causes the progressive loss of “executive functions” such as:
  - *Organizing and prioritizing*
  - *Controlling impulses*
  - *Beginning and ending activities*
  - *Creative thinking*
  - *Problem solving*



# Cognition

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- A student with JHD can continue his/her education with help from the school.
- For example, the cognitive disabilities in early stage JHD can often be mitigated with simple strategies using:
  - *Familiar routines*
  - *Breakdown of tasks*
  - *Temporary reduction of stimulus/distractions*
  - *Patience and a little extra time*
- More information is included in the “Best Practices” section of the disc.



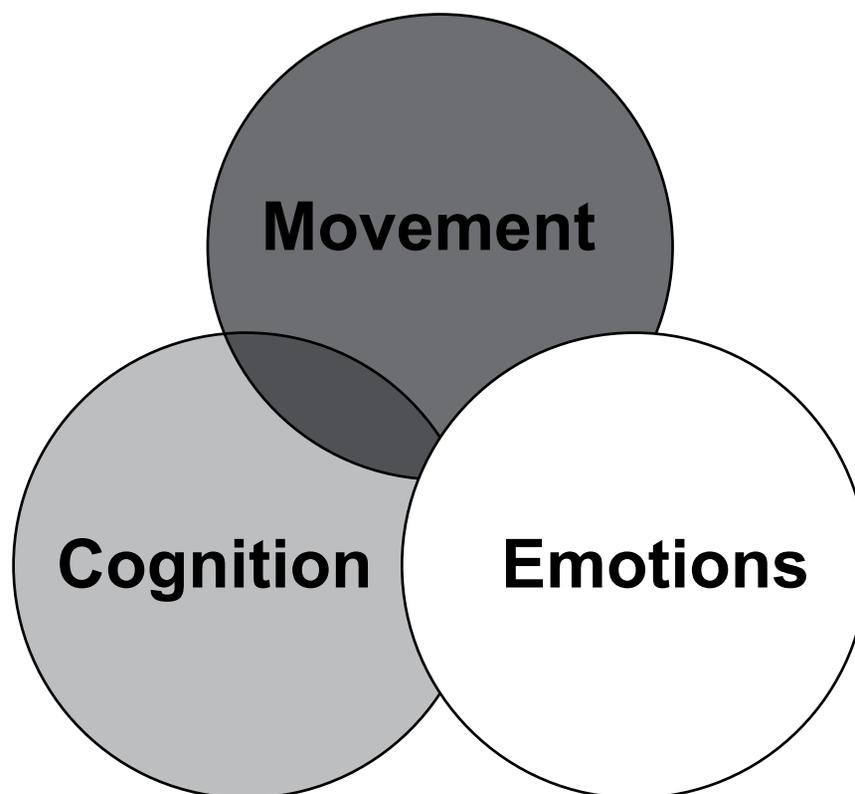
**“JHD is not just physical, it is the whole package. Until I realized that, I thought it was not that big of a deal.”**

*- School psychologist*

# The Connected Effects of JHD

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## 1. Emotional/behavioral disorders



# How does JHD affect emotions?

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- Among other things, JHD causes progressive damage to the nerve cells in the brain that regulate thoughts and feelings.
- Unregulated emotions may cause overreactions to everyday events:
  - *A minor annoyance triggers anger*
  - *Simple concerns become obsessions*
  - *Ordinary stimulation is overwhelming*



# Emotions/Behavior

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- Changes in behavior may be an initial indicator of the onset of JHD.
- Symptoms may include:
  - *Depression*
  - *Impulsive behavior*
  - *Aggression*
  - *ADD/Hyperactivity*
  - *Obsessive thinking*



# Emotions/Behavior

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- Sometimes, the unregulated emotions and behavior caused by JHD can be addressed with:
  - *Simple rules and goals*
  - *A quiet place for the student to withdraw*
  - *Separating the student from “trigger” individuals and situations*
  - *Medications*
- Apparent behavior problems may also be caused when the student is tired or confused.

# Emotions/Behavior

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- A student with emotional or behavioral disabilities caused by JHD can continue their education with help from the school.
- The student's neurologist and the school psychologist are valuable team members in monitoring and addressing the behavior issues triggered by JHD.
- More information is included in the "Best Practices" section of the disc.



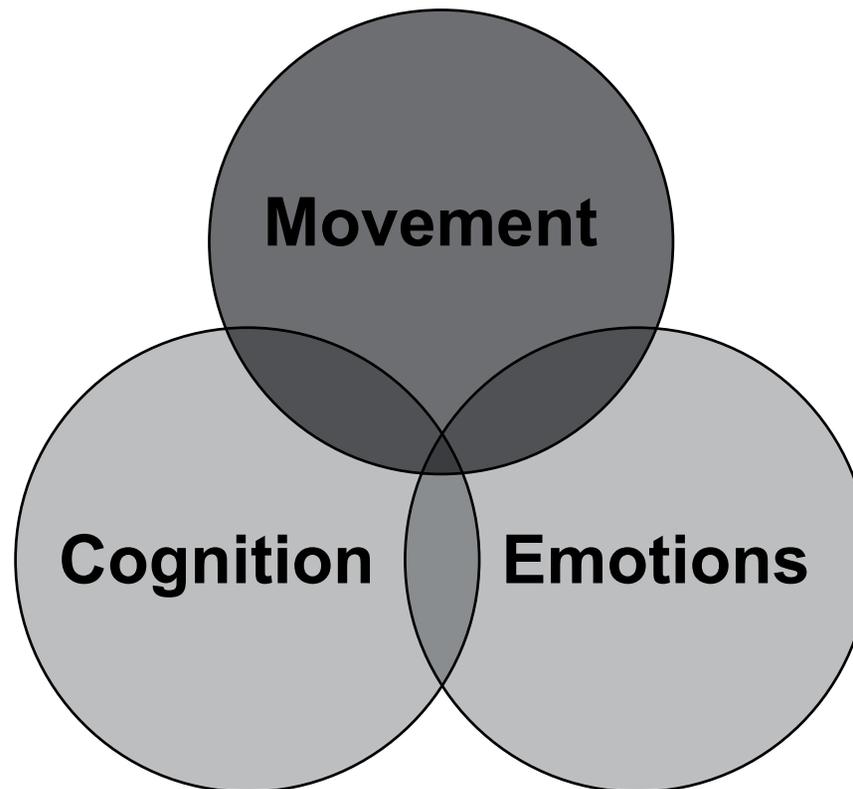
**“High functioning kids with JHD can have the most problems because they don’t look ‘sick’. People think they’re just acting out.”**

*- Mother of JHD teenager*

# The Connected Effects of JHD

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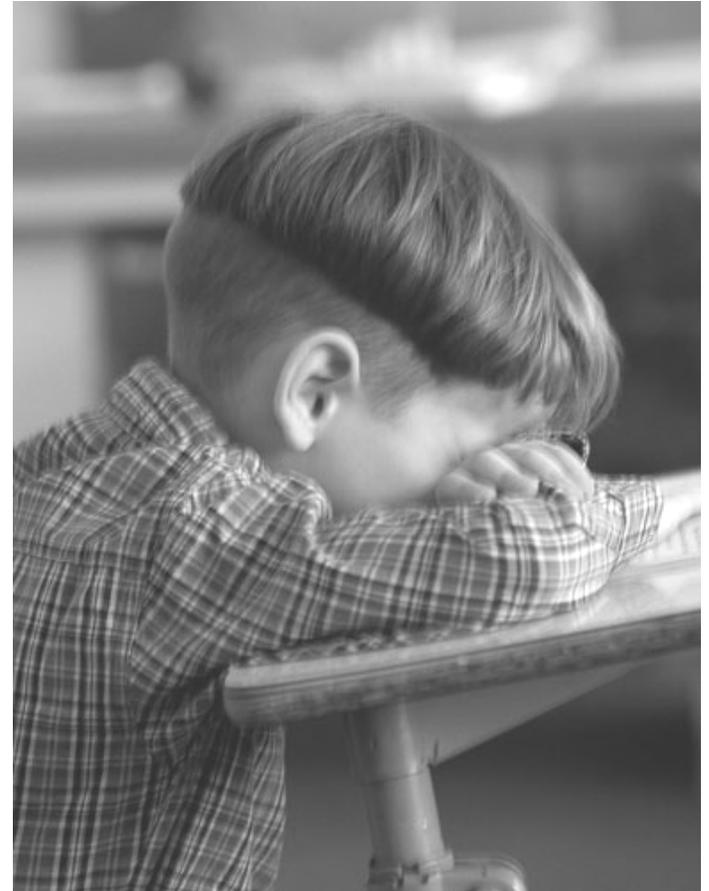
- The multiple disabilities of JHD combine to affect the entire person.



# The Student with JHD

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- In JHD, the various disabilities affect each other.
- For example:
  - *Difficulty speaking can make it hard to participate or ask a question*
  - *Hyperactivity may create a behavior problem*
  - *Depression can make it more difficult to organize a project*
  - *Loss of motor control will make test taking slow and confusing*



# Social isolation and inclusion

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- Social isolation is a common problem in JHD.
- Lack of knowledge and empathy can lead students and even teachers to misunderstand the symptoms of JHD and exclude or overlook the young person.
- Students with JHD should be included in important school activities and social events, especially as their condition will not improve over time.
- Like all students, young people with JHD deserve good memories of their time at school.

# The IEP and JHD

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- JHD is a disease that progresses at an uneven rate.
  - *Disabilities may increase slowly or rapidly.*
  - *JHD is unusual in the range and severity of symptoms it presents.*
- The Individual Education Plan (IEP) for a student with JHD may have to be amended during a single school year if the disease progresses.



**“Standardized tests are not an adequate measure for JHD, because there is so much individual variation.”**

*- Speech therapist*

# Stages of JHD Functional Scale

	<b>3 points</b>	<b>2 points</b>	<b>1 point</b>	<b>0 points</b>
<b>A. School Attendance</b>	No special assistance needed	Some regular classes, some special or modified	No regular classes	Does not attend school
<b>B. Academic/ Developmental Performance</b>	Reading, writing and math age appropriate	Mild decrease, still able to take a test	Unable to write legibly; able to communicate orally	Unable to read/write/ communicate orally
<b>C. Assigned Tasks</b>		Age appropriate	Occasionally assists	Unable to participate
<b>D. Activities of Daily Living</b>	Age appropriate	Requires some assistance	Assists others in self-care	Unable to assist
<b>E. Resides</b>		Home with only family assistance	Home/group home with non/family assistance	Long-term care facility

**11 - 13 points = Stage 1**

**7 - 10 points = Stage 2**

**3 - 6 points = Stage 3**

# Think about it...

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- Young people with JHD face many challenges.
- The disease affects motion, cognition and emotions.
- JHD can make it difficult to walk, talk and think clearly.
- It can cause a person to feel depressed, anxious or angry.
- JHD can leave a young person socially isolated.



# JHD in the school environment

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- The school environment should be safe, welcoming and inclusive for the young person with JHD.
- While young people with JHD will get help from school specialists, they also need understanding from teachers and students.



# Accommodating JHD in the school

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- There are cost-effective strategies that can accommodate the student with JHD at school.
  - *See the “Best Practices” section of the disc.*
- Included are strategies for aiding:
  - *Locomotion, seating and transportation*
  - *Speech, communication and eating*
  - *Cognition management*
  - *Social Integration*
  - *Physical fitness and more*



**“Our job is to keep life as normal as possible for as long as possible.”**

*- Speech Therapist*



# **Juvenile Huntington's Disease in the School: Understanding JHD**

## **Questions and Answers for Teachers, Students and Parents**

# Special Thanks

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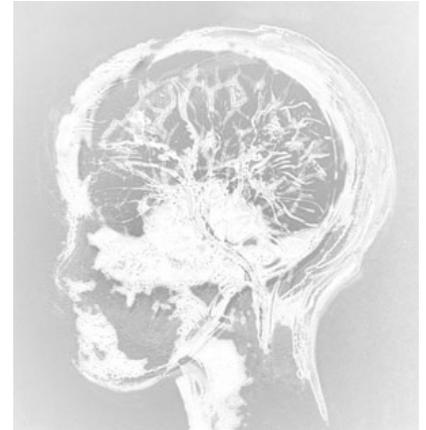


**HDSA wishes to thank  
the American Legion  
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Juvenile HD Program.**

# One of your classmates has Juvenile Huntington's Disease (JHD). What does that mean?

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- JHD is a disease that affects the brain.
- JHD affects how a person moves, thinks and feels.
- JHD gradually gets worse over many years.
- Your classmate has an illness that will never go away.



# HD and JHD

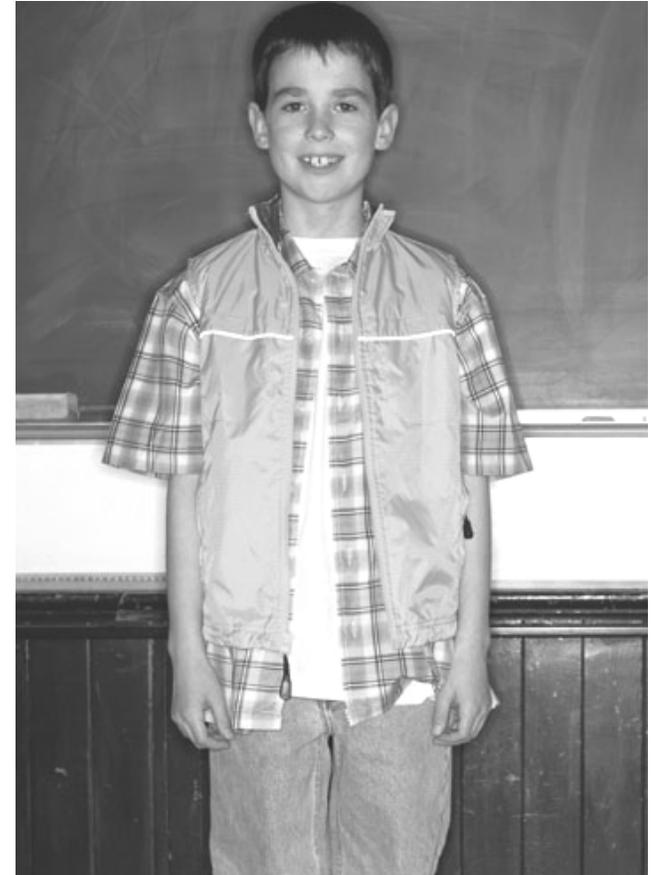
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- Juvenile Huntington's Disease (JHD) is a form of Huntington's Disease (HD).
- It is called Juvenile Huntington's Disease if symptoms begin when a person is under 18 years old.
- JHD causes some different symptoms and issues than HD that appears in adults.



# How does someone get JHD?

- JHD is a genetic disease.
  - *It is not contagious.*
  - *You cannot “catch” JHD.*
- Your classmate did nothing to cause JHD.
  - *He or she was born with the disease.*
- A child with JHD may have brothers and sisters who do not have the defective gene and who will never get the disease.



# How can you tell if someone has JHD?

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- There is no one way to tell that someone has JHD.
  - *JHD causes different symptoms in different people.*
- Because JHD affects the way people move, think and feel, it has some symptoms you can see and others you cannot.
  - *For example, some children with JHD have trouble walking, which is easy to see.*
  - *But JHD can also make a person easily distracted and forgetful.*
  - *Forgetfulness is a symptom you cannot “see.”*

# Is there a cure for JHD?

---

- There is no cure for JHD, but researchers are working hard to solve this problem.
  - *Doctors can use different medicines to make some of the symptoms better.*
  - *People with JHD have to live with the disease because there is currently no cure.*
  - *People with JHD deserve patience and understanding.*



# What is it like living with JHD?

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- JHD affects the brain.
  - *It can make simple things difficult.*
  - *For example, JHD can make it hard to walk, to write, even to talk and eat.*
- JHD affects thinking.
  - *It can make it hard to follow directions and learn new things.*
  - *People with JHD may forget things they used to know.*
- JHD affects emotions.
  - *It can make a person have a temper tantrum or get angry when they don't really mean to.*
  - *It is often the disease that is causing the problem.*

# What can the school do for your classmate with JHD?

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- Schools provide students with JHD the help they need to get an education.
  - *Some of the help comes right in the classroom. For example, the student may need extra time to take a test or a special chair to sit comfortably.*
- Some of the help may be done outside of regular class with special teachers trained to work with students who have disabilities.
- Schools provide JHD students with many kinds of support so that they can have a successful school experience.

# What can teachers do for a student with JHD?

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- Learn about the symptoms of JHD.
  - *Accept that the student with JHD is not lazy or “acting up” on purpose.*
- Be understanding when the student is forgetful.
- Be tolerant if the student needs more time to complete a task or needs the directions broken down.
- Look out for fatigue.
  - *Students with JHD tire easily and exhaustion can make their symptoms worse.*
- Remember that it is not possible for a JHD student to simply “try harder”.

# What can classmates do?

- Don't make fun of your classmate with JHD.
  - *Treat them like everybody else.*
  - *They want to be included in classroom activities and school projects.*
- Be patient and kind.
  - *Remember that your classmate with JHD did nothing to get the disease.*
  - *He or she was born with the disease.*



# What can classmates do?

---

- Be understanding if your classmate gets angry or frustrated.
  - *Because of JHD, sometimes they can't control their feelings.*
- Ask them to join you at lunch or at recess.
  - *It hurts to be "left out".*
  - *Be a friend and be there for them.*



# Everyone has things they do well and other things they don't do as well.

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- Over time, JHD will make it more difficult for your classmate to do things that they used to do well.
- They may not be able to do all their classwork or play sports the way they used to.
- Just because your classmate's abilities are changing shouldn't change the way you treat them.
  - *They are still your classmate and your friend.*
- Your classmate is learning to adapt to his or her changing abilities.
  - *You can adapt by not making a "big deal" out of it.*

# What about brothers and sisters?

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- Your classmate with JHD is part of a family.
  - *Their brothers and sisters need your support too.*
- Though your classmate has JHD, that doesn't mean their brothers and sisters have it too.
- Making fun of someone with JHD or of someone who has JHD in their family is hurtful and wrong.
  - *Imagine how hard it must be to see your brother or sister struggling with a serious disease like JHD.*
- Help the brothers and sisters of your classmate by treating them like everyone else.
  - *Be a friend and be there for them.*

# Be a good friend

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- Kids can be mean. Stick up for your classmate.
  - *If someone is making fun of your friend's disabilities, stand by them and let them know they are not alone.*
  - *If it gets bad, tell an adult.*
- If your classmate is moved to a special class where they can get more help, say “Hi” when you see them and treat them the way you always have.
- If your classmate with JHD is too sick to come to school, make them a card or call them on the phone.
  - *Don't stop being a friend just because they are not in school every day.*

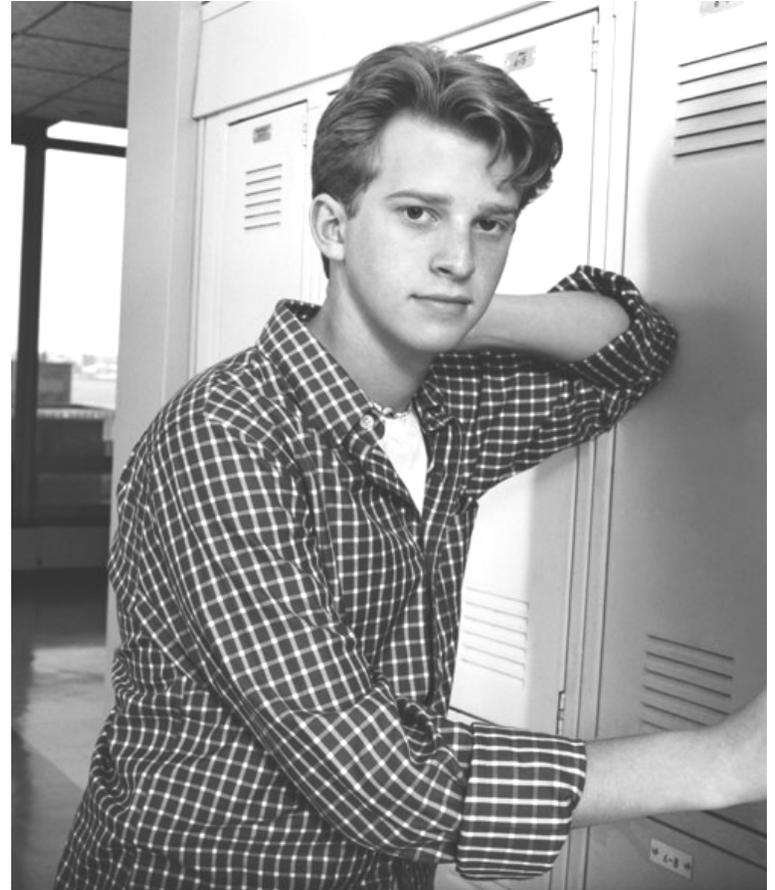
# To older students...

- JHD is going to affect your classmate's brain in many ways.
  - *It will change how they move, think and behave.*
  - *It will limit what they can do.*
- Accept your classmate for who they are inside and what they can do today.



# To older students...

- School is a very important place for people with JHD.
  - *It is where they get to be with other kids and feel like everyone else for a while.*
- JHD can make a person impulsive, aggressive or willing to do risky things. Don't let your classmate do anything unsafe.
  - *They don't really want to. It is the disease that is making them act that way.*



# To parents of classmates...

- Help your child to be a good friend to their classmate with JHD.
- School is the most important part of a child's life.
- Encourage your child to make school a positive experience for their classmate with JHD.
  - *Encourage them to treat their classmate with JHD just as they treat everyone else.*



# To parents of classmates...

- JHD can leave a child isolated and depressed.
  - *If you are organizing an after-school activity, club or event, invite your child's classmate with JHD.*
- Your child's classmate is facing a difficult disease.
  - *As symptoms advance, they may not be able to remain in school.*
  - *Encourage your child to remain in contact with their classmate even when they are no longer in school.*



# Think about it...

---

- Children with JHD face many challenges.
  - *The disease can make it difficult to walk, talk and think clearly.*
- Children with JHD get help from school specialists, but they also need help from teachers and students.
  - *To help a child with JHD, be patient and kind.*
- Understand that the disease may make simple things difficult for them.
- Everyone can help a child with JHD have a successful school experience.

# Who can you ask if you have questions about JHD?

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- The Huntington's Disease Society of America (HDSA) is an excellent place to get answers to your basic questions about JHD.
- They can also put you in touch with experts in your region, at the HDSA Centers of Excellence.
- HDSA can be contacted at 800-345-HDSA or [www.hdsa.org](http://www.hdsa.org)





# Meeting the Challenges of JHD

## Best Practices for the School Environment

# Special Thanks

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**HDSA wishes to thank  
the American Legion  
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Juvenile HD Program.**

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## Part 2:

- Behavior Aspects of JHD

## Part 3:

- Physical Aspects of JHD

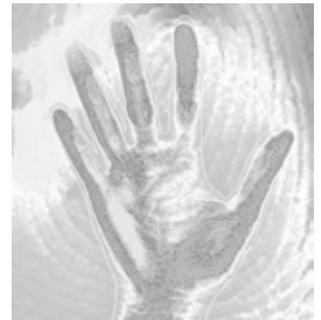
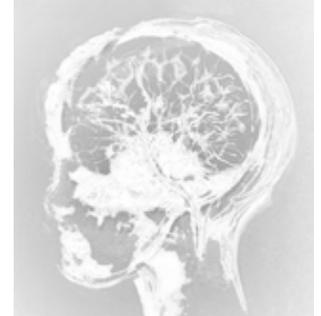
## Conclusions



# Introduction: What is Juvenile HD?

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- Juvenile Huntington's Disease (JHD) is a hereditary brain disease.
- Over time, this rare disorder causes increasingly severe disabling symptoms.
- No one can "get" JHD.
  - *It is an inherited genetic disease.*
  - *Only a person who is born with the defective gene can ever get the illness.*
  - *It is not contagious.*



# Outlook for a Student with JHD

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- JHD causes the progressive loss of nerve cells in the brain.
  - *This affects movement, cognition, emotions and behavior.*
- Currently, there are no treatments to halt the progression of the disease.
  - *The multiple disabling symptoms will become worse over time.*
- There are drugs and treatments which may help address some of the psychological, physical and emotional symptoms of the disease.

# Important Facts about JHD

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- As their disease progresses, young people with JHD face increasing difficulties with movement, cognition and emotional/behavioral issues.
- The symptoms of each young person with JHD will progress differently – some will show primarily physical symptoms and some will have cognitive or behavioral symptoms years before physical symptoms appear.
- JHD is a disease of many interrelated disabling symptoms.