IN THEIR OWN WORDS

Here's what some of our members have to say about YPAHD

STEVE, Age 13

"Thanks for putting your bios on the YPAHD website – nobody at school knows about HD, and it helps to know I'm not the only one growing up like this"

CRYSTAL, Age 19

"I'm really glad YPAHD exists! I feel too young to join a Chapter, but being on their online meetings is easy and actually really fun!"

SAMANTHA, Age 26

"Being involved with YPAHD has helped me so much – being so involved allows me to keep a sense of control over a disease that could otherwise feel overwhelming, and I've met such amazing people!"

VISIT US AT

@HuntingtonSC **facebook.com/ypahd**

OUR STORY

Family is at the heart of our community. Our families and volunteers tell a powerful story of caring people who pull together to improve the quality of life for Canadians impacted by HD. Huntington disease (HD) is a fatal hereditary brain disorder with devastating effects on both the mind and body. It is like having Alzheimer's, Parkinson's and Schizophrenia all at the same time.

The good news is, with recent medical breakthroughs many researchers and scientists believe that once we are successful in stopping the progression of HD we will also find the answers to many other neurological diseases. Your valued support will bring us one step closer to this goal.

The Huntington Society of Canada a not-for-profit charitable organization which raises funds to deliver individual and group counseling service to support individuals and families living with HD and to find medical research to delay or stop the progression of the disease. The Society also works with health and social services professionals who interact with people with HD, educating them on the disease so they can better serve their clients.

HUNTINGTON DISEASE FACTS

- HD is a fatal hereditary brain disorder
- A child born to parent with HD has a 50% chance of sharing the same fate
- 1 in every 1,000 Canadians is directly or indirectly impacted by HD
- Currently there in no cure for HD

Huntington Society of Canada
HUNTINGTON
Société Huntington du Canada

FOR MORE INFORMATION:

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Huntington Society of Canada
HUNTINGTON
Société Huntington du Canada

YPAHD Young people affected by huntington disease

HELPING YOU BEGIN YOUR JOURNEY WITH HUNTINGTON DISEASE

www.ypahd.ca **ypahd@huntingtonsociety.ca**

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WHAT IS YPAHD?

We are a virtual chapter of the Huntington Society of Canada (HSC) that is made up of young people faced with challenges associated with Huntington disease (HD). Our goal is to provide a community and support network for youth and connect them with HD initiatives in Canada and all over the world. We can help you as you face situations such as;

- finding out that the HD gene runs in your family
- genetic discrimination
- coping with a parent who has HD
- considerations around genetic testing
- concerns you may have about starting your own family

You no longer need to feel isolated or alone with your concerns. We can help you along your journey with HD.

OUR MISSION

- YPAHD aspires to a world free from Huntington disease

YPAHD STRIVES TO

- increase public awareness of HD, thereby enabling others to understand the disease
- raise funds to deliver services for those living with HD and to further research in order to slow and prevent HD
- listen and advocate for the needs and goals of youth through the communication mechanisms provided by HSC

The executive is composed of youth ranging from age 16 to mid-30's. Please know that many of us have already been where you are today, and we understand what you are facing.

WHAT IS HUNTINGTON DISEASE?

Huntington disease (HD) is an inherited brain disorder. It was named after the doctor who first described it in 1872 – George Huntington – and it used to be called Huntington's chorea. HD causes cells in specific parts of the brain to die: the caudate, the putamen, and as the disease progresses, the cerebral cortex. As the brain cells die, people with Huntington's become less able to control movements, recall events, make decisions and control emotions. The disease leads to incapacitation and eventually death.

WHO GETS HD?

It is estimated that one in 7,000 Canadians has HD and approximately 5 in every 10,000 are at risk of developing the disease. Many more are touched by HD whether as a caregiver, a family member, or a friend. It is a genetically dominant disorder which means that each child of a parent with HD has a 50% chance of inheriting the disease. Males and females have the same risk of inheriting HD and it occurs in all races.

Primarily HD affects adults. Symptoms usually appear between the ages of 30 and 45, but the disease can first appear in children as young as 5 or in adults in their 70's.

WANT TO GET INVOLVED?

MEMBERSHIP:

It's free to become a member of YPAHD. All you have to do is go to the website, and Get Connected. Someone will contact you and ensure you're on the email list to receive current updates with all of YPAHD's activities.

LEADERSHIP OPPORTUNITIES:

We are always looking for volunteers and new ideas to support education and awareness of HD. If you want, you could become a leader in your community. YPAHD members organize their own events, serve on the executive, help with the planning of the semi-annual National Conference, and have even been interviewed by local media. If you're interested, we'd love to hear from you. Be sure to contact us with your ideas!

EVENTS:

We participate in many fundraising events throughout the year that connect our local HD communities. Visit our website for upcoming events in your area.

teamHD

If you like to run, you could take the Running Challenge and become a member of TeamHD, our Nation-Wide Running Team. Visit **www.teamhd.ca** for more info.