

Celebrating 40 years!



Huntington Society of
Canada's 40th Anniversary
Campaign:

Grassroots to Mountaintops.
Building a new chapter in our
history starts now.

The Grassroots to
Mountaintops campaign goal
is to raise \$5 million to meet
critical needs.

With the help of our strategic
partners and supporters, the
Huntington Society of Canada
continues to be an innovator
by creating opportunities
across Canada.

To learn more click here.

Enroll!

Updates from the Enroll-HD
global community



Enroll-HD is a very exciting
global initiative that is a
planning and consultation
process for clinical trial
registration for Huntington
disease.

Publications and fact sheets
are available on the HSC
website in the following
categories: Individuals
with HD; Those At-Risk;
Caregivers; Families;
Professionals.

www.huntingtonsociety.ca

Strength & Knowledge

Helping Children Cope

May 23, 2013
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Children from families affected by Huntington disease (HD) face challenges that most children their age do not. Children know and see what is happening and will see a parent or loved one change as the disease progresses. They need support and understanding.

HD does not have to take over a young person's life. Here are a few ways that you can help your children cope:

Ensure your children's needs are met

Children need food, shelter, clothing and love, but make sure they also have a chance to enjoy friends, fun and attention. Reassure your children that their needs are just as important as the needs of their parent with HD.

Provide information about HD

It is important for children to know what HD is and how it is going to affect their parent and themselves.

- Encourage your children to ask questions any time.

- Listen to your children's concerns, fears, and worries.

Reassure your children

Frequently reassure them that they will always be cared for and that you love them.

Ensure they have an emotional outlet

It is important that your children have people they can talk to about their feelings. Anyone who can listen is a support: a parent, friend, teacher, or another young person who is at risk. Even talking to a pet, a stuffed animal or a doll can help.

Painting a picture to express their feelings or writing about them can also help. Corresponding with an email or pen pal might be beneficial.

Let children know that their feelings are normal, not crazy or bad. Encourage them to share problems and concerns as this is a good first step to overcoming them.

Many people feel better knowing that they are not alone in having to face HD.

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Call for Nominations

If you, or someone you know, may be interested in serving as a member of the Huntington Society of Canada's Board of Directors, please let us know. There is a process that we follow and expertise that we are looking for, but it starts with your interest. If you want to learn more please

forward your CV and Letter of Interest outlining your skills and the value you bring, to Huntington Society of Canada, 151 Frederick St., Suite 400, Kitchener, ON, N2H 2M, Attention: HSC Board. We will review your CV and letter if received by June 20, 2013 and we will be in touch.

EHDN's Standards of Care for HD patients

"The most comprehensive effort so far to document best practice in the clinical management of HD".



EUROPEAN HUNTINGTON'S DISEASE NETWORK

Be sure they have free time

Set aside time for your child to be with friends.

Living with HD day in and day out can create stress. If it's possible, arrange a break for your children. This could be a holiday without the affected parent or a time at summer camp.

Don't give them too much responsibility

Children shouldn't have to take on adult tasks and worries. If you're finding that you need more help, seek out support services in your community, such as home care, respite, etc.

Set firm, clear limits and follow through effectively

You may be tempted not to push your kids because they're dealing with enough as it is. Be flexible, however, all children need clear limits and consistent discipline.

Foster positive interaction between your children and the parent with HD

Arrange enjoyable outings or activities together if possible. These activities will maintain a positive relationship and create happy memories. Quiet times at home can also be positive. This could involve looking at family pictures, bedtime stories, or cuddling on the sofa while watching TV.

Encourage relationships with other adults

Encourage children to become involved with other adults or older youth, such as a friend's parent, an aunt, uncle or older cousin.

This will provide them with an additional role model. It will also give them the opportunity for more activities and fun. This is especially important if the parent with HD is in the advanced stages.

Be sure your children know where they can get help during a crisis

The Kids Help Phone (1-800-668-6868) is a toll-free, bilingual telephone counselling service for children and youth. It provides emotional support, counselling, information and referrals. Local communities have crisis support lines.

Sources for support and information

- Your local Huntington Society of Canada (HSC) HD Resource Centre or FS Worker can provide information and support to all members of the family.

- Become involved in a local HSC Chapter so your children can meet other families.

- YPAHD (www.ypahd.ca) is a virtual youth chapter of HSC made up of young people faced with challenges associated with HD.

- HDYO (www.hdyo.org) is an international youth organization which is an excellent source for youth-oriented information.

Original Source: "Reaction to Huntington Disease: Focus on the Child," prepared by Sandra Funk, Manitoba Resource Centre, for a 2003 conference presentation. Updated 2013 with input from Resource Centre Directors: Sally Vincent (Northern Alberta) & Teresa Jarosz (Toronto)

Special Announcement Regarding NITOMAN® (tetrabenazine)

Recently, Valeant Canada introduced the NITOMAN® Patient Choice Program for all patients who are prescribed NITOMAN also known as tetrabenazine tablets.

The NITOMAN Patient Choice card will cover the difference in medication ingredient cost between the brand NITOMAN and the generic alternative. This cost will be covered by Valeant Canada.

Cards can be obtained from your physician, online by visiting www.nitomansupport.ca or through your local Huntington Society Resource Centre Director or Family Service Worker.

For more information visit www.nitomansupport.ca, contact your doctor or your local Huntington Society Resource Centre Director. For a list of HSC Resource Centre Directors please visit the Huntington Society of Canada at www.huntingtonsociety.ca.

 young people affected by
huntington's disease
www.ypahd.ca



HUNTINGTON'S DISEASE
YOUTH ORGANIZATION

HSC is a proud supporter of
**HDYO an International
organization to help young
people who are affected by HD.**
Visit www.HDYO.org

Staying Connected

Please visit our **website** and fill out our confidential contact information form to receive email communications from HSC. According to your preferences, we'll communicate with you in confidence by email about research findings, clinical trials, best practices of care, local and national events and happenings, volunteer opportunities, etc.

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