Volunteer Training Initiative

VTI

Level 1

Huntington Society of Canada
HUNTINGTON
Société Huntington du Canada

Introduction to the Huntington Society of Canada's Volunteer Training Initiative

What is the HSC's new Volunteer Training Initiative?

- Part of the Huntington Society's commitment to give volunteers the tools they need to contribute to the Huntington's cause
- An opportunity for volunteers to learn more about Huntington disease, the Society and its work
- A chance to feel a part of a bigger network of volunteers who are all working hard to accomplish the same things

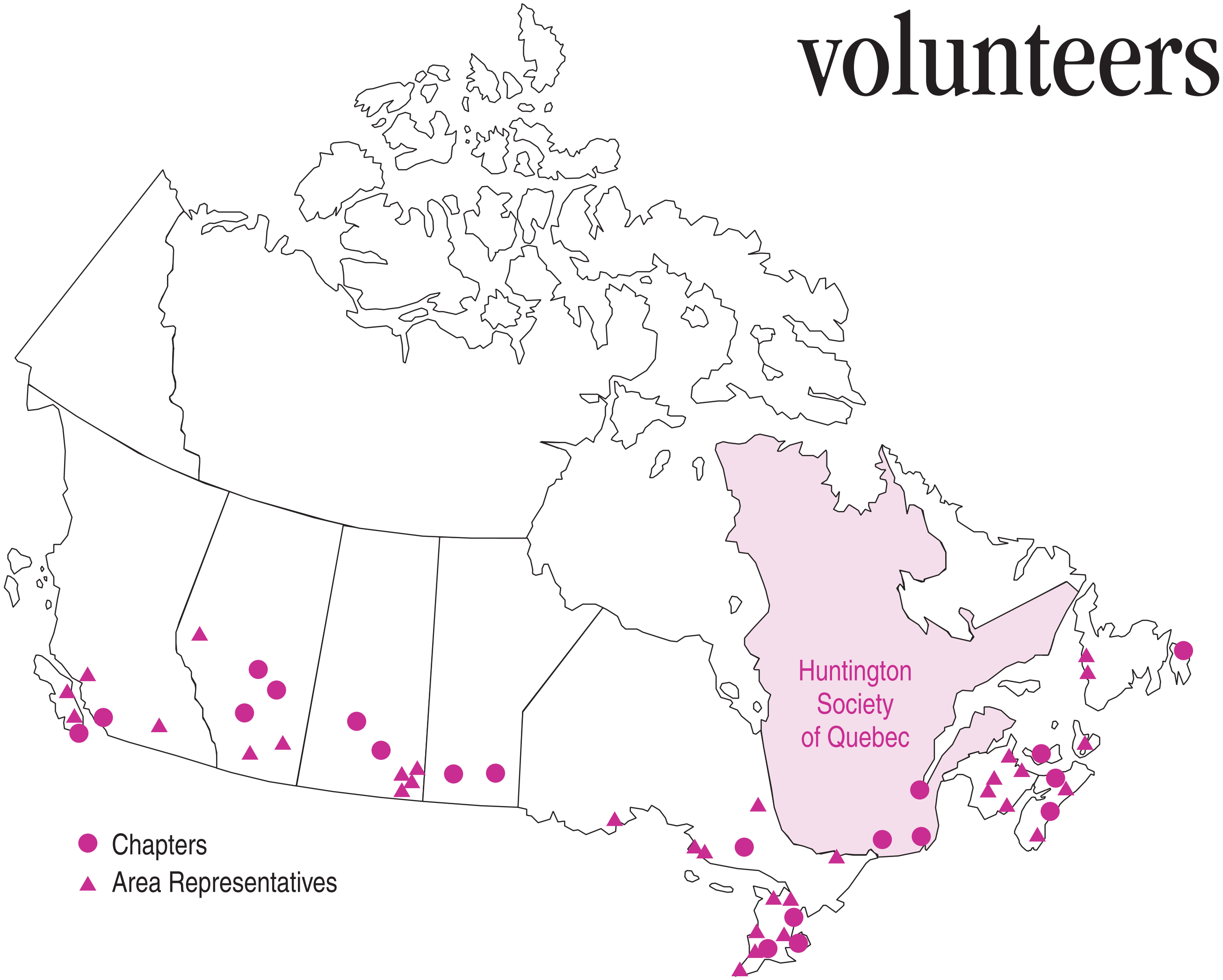
What does it mean to be an HSC volunteer?

- Being part of an organization that is committed to putting individuals dealing with HD FIRST
- Contributing to the search for a cure through fundraising and communications activities
- Being part of a support network for families dealing with HD

What will I get out of being a volunteer for the Huntington Society?

- Feel good about helping/contributing to a cause
- Develop new skills
- A chance to give back to your community

Where are all the volunteers?



What do volunteers do?

Huntington Society volunteers are organized in two ways:

Chapters are located in communities where a group of volunteers has organized itself to take on a number of key responsibilities on behalf of the Society. This includes fundraising (such as the Indy, Amaryllis campaign and other local projects) and public awareness, as well as support for local HD families.

Area Representatives are individual volunteers who represent the Society in their community independently. They can be involved in the same types of activities as Chapters, but often on a smaller scale.

Inside Track

Once a year (and always in a different part of Canada), the Huntington Society of Canada holds its Annual General Meeting and Conference. This is an opportunity for volunteers to come together and provide input into the direction of the Society, to share their experiences with other volunteers, and to attend workshops aimed at skill development in areas such as fundraising, communications and volunteer development.

“Excuse me, what is Huntington disease, and is anybody doing anything about it?”

What do I need to know about Huntington disease?

Huntington disease …

- is a hereditary, genetic brain disorder that affects both mind and body
- has onset (on average) in mid-life
- is fatal — there are no treatments yet

You could say …

"Huntington disease is a fatal, hereditary brain disorder that affects both mind and body."

Inside Track

Huntington disease is named for the Dr. George Huntington, who was the first person to describe the symptoms of the disease in 1872.

What is the Huntington Society of Canada?

Huntington Society of Canada …

- is the ONLY national health charity dedicated to the fight against HD
- is a voluntary organization
- raises money to fund programmes in research, services and education

You could say …

"The Huntington Society of Canada is a national health charity that raises money for programmes in research, services and education."

Inside Track

The Huntington Society of Canada was founded by Ralph and Ariel Walker in 1973…from the kitchen table of their home!

“Show me the money!”

How does the Society raise money?

- National Programmes: e.g. Indy, Amaryllis, individual giving, corporate appeals, bequests
- Community Programmes: e.g. bingos, walks/hikes, golf tournaments, garage sales
- Partnerships: e.g. Co-op Atlantic, CB Richard Ellis, Dynafit, etc.

You could say …

"The Huntington Society raises money in different ways, such as national events like the Indy, local fundraisers like our garage sales, individual donations, and partnerships with business."

Inside Track

Fundraising by Huntington Society volunteers accounts for more than 50% of all the money the Society raises in a year!

Where does the money go?

For 2000-2001 the Society had total revenues just under $2 million

- 15% was spent on Research
- 43% was spent on Family and Individual Services
- 13% was spent on Education and Awareness
- 15% was spent on Administration and Fundraising
- The remainder goes to a combination of Governance & Accountability; Special Initiatives; Meetings & Workshops; and Volunteer Training & Development

You could say …

"The Society spends its money on programmes in research, services and education. Only 15% of the money it raises goes to administration and fundraising."

How do I know the Society is spending the money the way it says it is?

The Huntington Society of Canada …

- is a registered charity with reporting requirements to Revenue Canada
- is audited every year by an independent auditor
- subscribes to the Canadian Centre for Philanthropy's *Ethical Fundraising and Financial Accountability Code*

You could say …

"You know the money is going where it should because the Society reports every year to Revenue Canada, and is audited every year."

How much money does the Society get from the government?

- Very little … in 2000-2001, funding from the government was 6% of total revenues

You could say …

“The Huntington Society is mainly independent of government funding. Money from the government makes up only 6% of money raised in a given year.”

Inside Track

Money from Health Canada was used to develop the VTI.

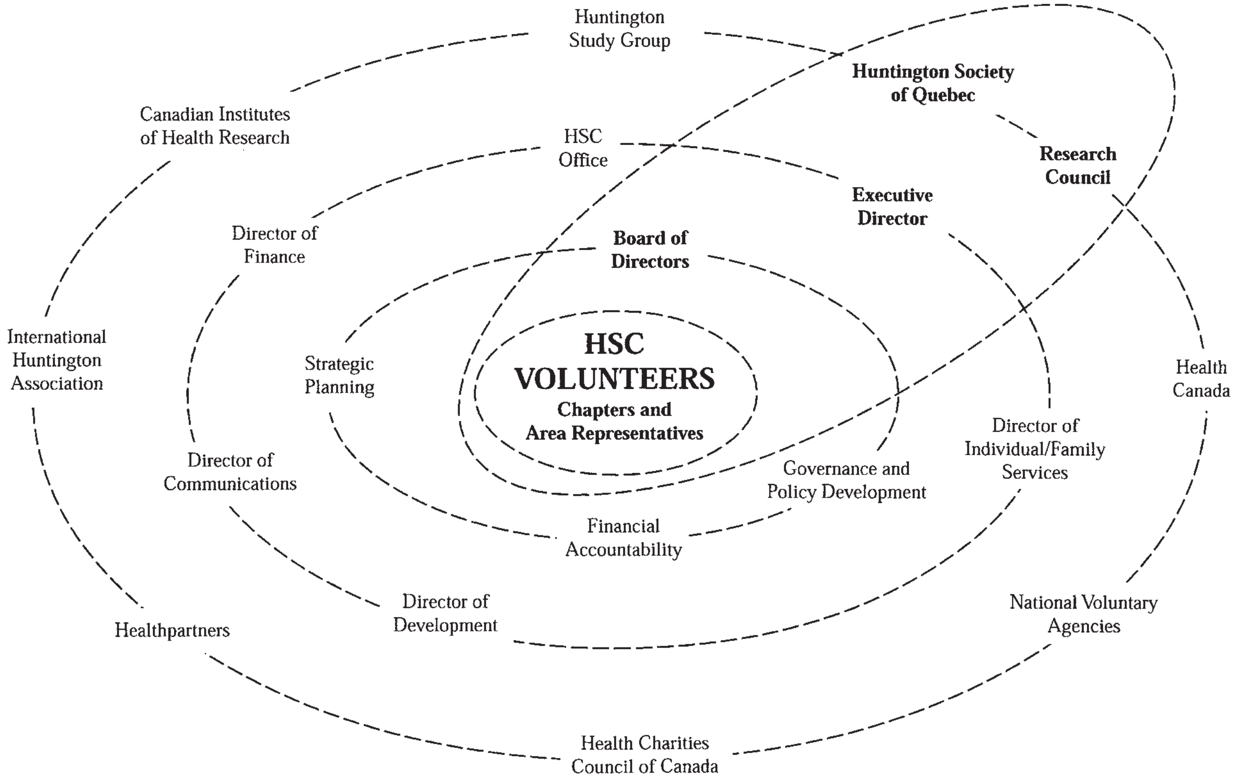
More about what the Huntington Society does

How big is the Huntington Society of Canada?

Inside track

- Governed by a national, volunteer Board of Directors
- The Society is made up of a national network of volunteer Chapters and Area Representatives
- Society's office in Kitchener employs 10 full-time staff
- Society pays for 10 Resource Centres across Canada staffed by full-time and part-time social work professionals
- There are 12 Support Workers who are social work professionals working part-time in areas not served by Resource Centres

Huntington Society of Canada Organizational Chart



What is happening in Huntington's research?

- Identified the gene that causes HD in 1993 — can now tell people whether or not they have the gene
- Developing a better understanding of what the disease does – identifying possible strategies for a cure
- Testing new drugs that might help slow down the progress of the disease

You could say …

"Researchers are making progress in Huntington's research every day. Right now they're testing drugs as possible treatments, and they are looking for a cure."

Inside Track

Researchers are currently working towards drug trials for several different drugs (including minocycline and creatine), that have been shown in animal models to slow the progress of the disease.

What services do you provide for individuals or families?

- Resource Centres (including education of health care professionals)
- Support Workers
- Educational material

You could say …

"The Society has a range of services for individuals with HD and their families, such as Resource Centres, Support Workers, and the latest information about the disease."

Inside track

The Society has brochures that explain all the services available from its Resource Centres and Support Workers … just ask for them.

When you say “public awareness,” what do you mean?

- Huntington Disease Awareness Month
- Articles and stories in the local newspaper and on the radio
- Letting people know about fundraising events

You could say …

“The Society’s public awareness programme is all about volunteers from across Canada ‘getting the word out’ any way they can, including: mall displays, posters on information boards, interviews with local media, public speaking, etc.”

“What’s next?”

What do I do if someone asks me a question I don't know the answer to?

Step 1: Don't panic

Step 2: Be honest…say, "What a great question" and explain that you don't actually know the answer

Step 3: Make sure you say, "I know where I can find that out. Can I get back to you?"

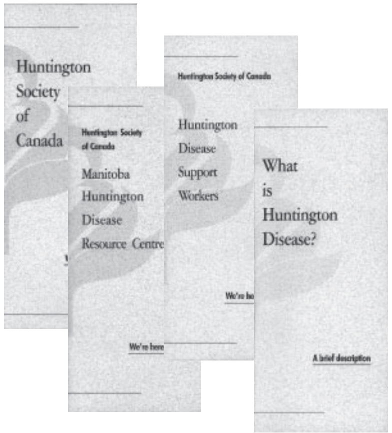
Step 4: If you're not sure how to find the answer, call us; we'll get the answer for you

Step 5: FOLLOW UP…always get back to the person, even if it's to say, "I still haven't found the answer, but I'm working on it!"

I learned a lot here, but what if I forget?

There are materials available to help you remember . . .

- This workbook
- *Huntington Society of Canada: We're Here to Help* brochure
- *What is HD?* brochure
- Huntington Society of Canada Annual Report
- *Horizon*



Huntington Society of Canada

Huntington Society of Canada
Manitoba Huntington Disease Resource Centre
We're here

Huntington Society of Canada
Huntington Disease Support Workers

What is Huntington Disease?
A brief description

Huntington Society of Canada
HORIZON
Société Huntington du Canada

TOWARD NEW TREATMENTS FOR HUNTINGTON DISEASE

INSIDE

IT'S TOMORROW NOW
HUNTINGTON SOCIETY OF CANADA

. . . or you can call us at 1-800-998-7398

Now that I have a better handle on this stuff, where do I go from here?

- Remembering what you learned is only one piece of the puzzle…we want you to use it
- Talk to friends, neighbours, co-workers about your volunteering with HSC
- Think about what you might like to do (e.g. fundraising, media relations, etc.)
- Get more involved in the activities of your Chapter
- Talk to staff at the Huntington Society about how you get more involved