

# Donor Dollars at Work

## How We Invest Donor Dollars

**“The Huntington Society of Canada is to be congratulated on an excellent, high quality and effective program in research into the treatment of, and a cure for, Huntington disease ... HSC has received an excellent return on their investment in Huntington disease research.”**

*Results of the 2013 Commissioned Report to assess the value of research investments made by HSC.*

### Our Mission

The support of our donors makes it possible for the Huntington Society of Canada to aspire to a world free from Huntington disease.

The Society strives to:

- Maximize the quality of life of people living with HD by delivering services;
- Enable others to understand the disease; and
- Further research to slow and to prevent HD.

## Transparency and Accountability at HSC

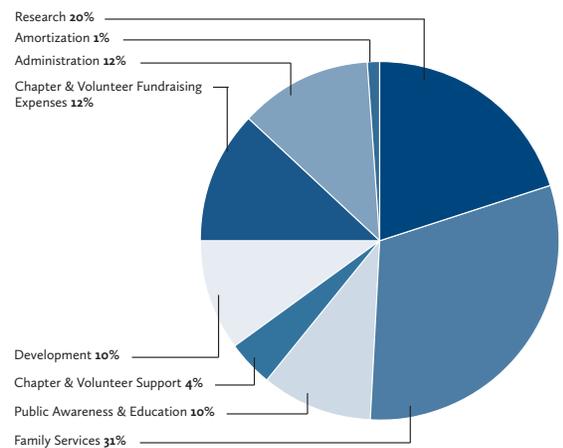
**Our goal** is to provide the highest level of hope for families affected by Huntington disease (HD) by funding crucial research and to help them live their best possible lives by providing services, education and advocacy.

**Our commitment** to our donors is to provide a status update on our strategic goals on an annual basis to ensure we are fully accountable and transparent.

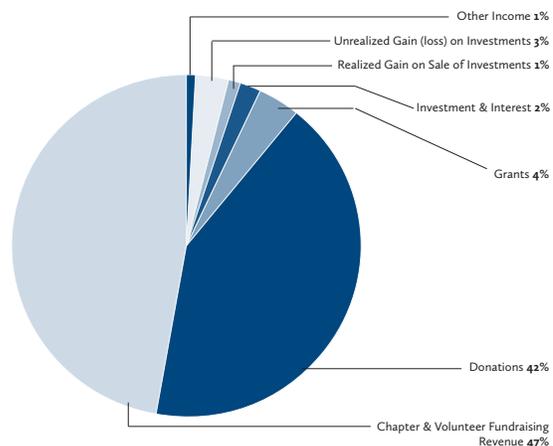
**The Huntington Society of Canada** is a member of Imagine Canada.™ Imagine Canada sets the standards for charitable organizations in managing and reporting their financial affairs. As a member, the Huntington Society of Canada follows Imagine Canada’s ethical guidelines as outlined at [www.huntingtonsociety.ca](http://www.huntingtonsociety.ca).

**Of every dollar the Huntington Society of Canada receives, we allocate the majority of funds to research and services, and a small percentage to education, advocacy and awareness.**

### Expenditures



### Revenue



NOTE: The information presented is based on the Society's financial results for 2013.

# Meeting Our Targets

How do you turn a strategic plan into reality? Our dedicated donors, volunteers, staff and board members keep us on target.

## Invest in world-class research that will lead to treatments to slow and prevent Huntington disease

### Strategic Focus

- Increase our investment in globally recognized research leading to effective treatments.
- Strengthen the foundation for clinical trial research in Canada.

### 2013-2014 Highlights

- HSC-funded research led to new therapeutic targets and methods for large-scale drug screening.
- For the first time, HSC was able to fund every promising research proposal we received, committing \$150,000 in New Pathway grants and \$450,000 in NAVIGATOR grants.
- Our roundtable discussions on clinical trial readiness, funded by Rx&D, brought together over 20 researchers, scientists and clinicians from across Canada.

## Continue to advocate for families and individuals living with HD and enhance the services we provide them

### Strategic Focus

- Prepare the HD community for a potential treatment through increased awareness of predictive testing and clinical trials.
- Identify gaps of support to HD communities and work to fill those gaps.

### 2013-2014 Highlights

- Over 200 participants across the country attended our Fall Symposium—in person or online—to learn more about predictive testing and clinical trials.
- We recruited Jonathan Genest-Jourdain to our Board of Directors, providing an important perspective on serving remote communities and First Nations families.
- We expanded our family services by opening a new Southwestern Ontario Resource Centre, based in London.
- Newfoundland HD Multidisciplinary Clinic opened on September 17, 2013.

## Increase awareness of HD and HSC

### Strategic Focus

- Develop and implement a short, medium and long-term public relations, communication and marketing strategy.

### 2013-2014 Highlights

- In fall 2013, we launched a new, easy-to-navigate website.
- We updated existing and expanded our fact sheets, giving families and professionals more of the information they need.
- We increased our social media presence, nearly doubling the number of Facebook likes and increasing Twitter followers by 37%.



## Demonstrate leadership locally, nationally and globally

### Strategic Focus

- Collaborate and play leadership roles with strategic partners and external stakeholders.

### 2013-2014 Accomplishments

- Our advocacy efforts for genetic fairness in Canada reached a significant milestone when the federal Speech from the Throne in October 2013 identified this issue as a key priority.
- We worked with Senator James Cowan to advance Bill S201, the most comprehensive genetic non-discrimination bill to date, which passed second reading in the Senate in April.
- We continued to advance the Huntington's cause as active members of the Canadian Coalition for Genetic Fairness, Neurological Health Charities Canada, Health Charities Coalition of Canada and Health Partners.

## Strengthen the focus on young people affected by HD and enhance the service we provide them

### Strategic Focus

- Continue to enhance development of youth programs and tools.
- Increase youth participation within HSC and the HD community.

### 2013-2014 Accomplishments

- Our Youth Mentorship pilot program recruited its first mentees and successfully matched them with trained mentors.
- We worked closely with Young People Affected by Huntington Disease (YPAHD) to plan the second HSC Youth Conference, happening in October 2014.
- We secured funding to ensure the sustainability of this important initiative.

## Ensure financial and organizational stability, effectiveness and excellence

### Strategic Focus

- Increase revenue and funds available for mission.
- Enhance financial and organizational processes to build efficiencies, manage risk and build capacity.
- Retain and nurture a high-performing team.

### 2013-2014 Accomplishments

- Thanks to significant contributions from new donors and outstanding fundraising by our Chapter volunteers, this year's revenue exceeded targets.
- Expenses were managed well, coming in lower than budgeted.
- Staff attrition was kept below the industry standard of 25%.
- We successfully completed the Articles of Continuance process under Canada's new Not-for-profit Corporations Act, including updated Board by-laws and personnel policies.