



## The Huntington Society of Canada's Output and Outcomes

Updated: Fall 2017

<b>Strategic Goal:</b>	<b>Output</b>	<b>Outcomes</b>
<p>1) Strengthen the foundation for clinical trials in Canada</p>	<p>Increase number of Multi-disciplinary clinics.</p> <p>Continue development of youth programs and increase youth participation with HSC and HD.</p> <p>Continue advocacy efforts both federally and provincially, to end genetic discrimination.</p> <p>Support clinical research.</p>	<p><b>2012 -2013</b> St. John's Newfoundland - Multi-Disciplinary Clinic with attending HSC Social Worker established First of its kind Youth Day is created by youth, for youth affected by HD supported by HSC management.</p> <p><b>2014 – 2015</b> HSC's Youth Mentorship Program continued to strengthen and grow and the second round of mentor recruitment, selection and training was completed. 14 youth mentors trained and 14 youth mentees matched.</p> <p><b>2016</b> Bill S201, An Act to Prohibit and Prevent Genetic Discrimination, passed second reading in the House in late September. The American Society of Human Genetics honoured Senator James Cowan and HSC CEO Bev HeimMyers with the American Society of Human Genetics Advocacy Award for moving Canada forward regarding the protection of genetic test information.</p> <p><b>2017</b> Bill S201, An Act to Prohibit and Prevent Genetic Discrimination, passed 3<sup>rd</sup> reading in House, April 4, 2017 and given Royal Assent on May 4, 2017 which resulted in protection of genetic test information for all Canadians. HSC is recommended, by N2 and CTO, to four organizations to share their work on the HD National Strategy on Clinical Trials in Canada. Tools created by HSC and shared: Clinical Trial Preparation Guide, Clinical Trials Check List, Clinical Trials Map, Mentorship Program (matching seasoned clinician scientists with novice clinician scientists).</p>

<p>2) Continue to provide and enhance services to Families and Individuals living with HD.</p>	<p>Identify gaps of support to HD communities and work to fill those gaps.</p> <p>Create opportunities and reduce barriers to reach out to HD families and individuals and have them reach out to us.</p>	<p><b>2014 – 2015</b> New HD Resource Centre was established in London, Ontario 2014 HSC National Conference was hosted in Winnipeg, Manitoba</p> <p><b>2016</b> Over a dozen customized HD educational modules were published for Family Services Hours were increased for services to families in New Brunswick and in Kingston, Ontario and surrounding areas</p> <p><b>2017</b> HSC opens new HD Resource Centre in Moncton, New Brunswick to support those living with HD in the province</p>
<p>3) To be seen as a leader both nationally and globally</p>	<p>Continue to fund globally recognized excellent research.</p> <ul style="list-style-type: none"> <li>• Set the stage for clinical research in Canada.</li> <li>• Continue to build critical mass of HD research in Canada while encouraging global collaborations.</li> <li>• Influence a made in Canada solution through advocacy efforts to end genetic discrimination.</li> <li>• Continue and enhance our leadership role in the HD global youth movement.</li> <li>• Increase global collaborations with HD Service providers and organizations.</li> </ul>	<p><b>2012 -2013</b> Dr Simonetta Sipione, HSC funded researcher at University of Alberta, successfully reversed HD motor symptoms in a mouse model bringing the mice back to normal Be Brave, Be Bold, Be Ready: Clinical trial initiative meeting held in the fall was the first of its kind in bringing together researchers, clinicians and family members to develop a national HD Clinical Trial strategy Dr. Ray Truant discovered that huntingtin protein bends differently than the protein from a normal gene and proved that normal shape can be restored (HSC funded research). Review of HSC’s research funding over the past 15 years was completed. The quality and outcomes of the research supported by HSC is reported to be excellent. Most important is that other scientists are building on the research HSC funds. A small pharmaceutical firm, IONIA, partnered with the pharmaceutical giant Roche to launch Phase I clinical trials of a drug currently known as IONIAHTTRx which targets the messenger RNA that holds instructions for making the faulty HD protein, IONIA-HTTRx attacks the root of the problem. Both companies believe their gene-silencing approach could mean treatments for the thousands of Canadians diagnosed with Huntington disease and for the thousands more at-risk of developing it</p> <p><b>2014</b> - HD Consortium was officially formalized <b>2015</b> – HSC launches HD Clinical Trial Map locator making it easier for the HD Community to see what trials are offer, where and who to contact <b>2017</b> - HD-COPE is announced: In 2017, the European Huntington Association (EHA), Huntington’s Disease Society of America (HDSA) and Huntington Society of Canada (HSC) created the Huntington’s Disease Coalition for Patient Engagement (HD-COPE), in an effort to give families who are affected by Huntington disease (HD) a direct and</p>

		<p>impactful voice in HD clinical research. HD-COPE is a conduit between pharmaceutical companies, researchers and individuals, who are impacted by HD. The HD-COPE Advisory Board, represented by the senior staff of each member organization will provide counsel to clinical research leaders on broad issues involving patient feedback, community needs and research recruitment.</p> <p><i>One gene, one cause, one disease ....and the research implications on other neurodegenerative diseases.</i> Recent Huntington disease research, supported by HSC, shifted the research focus to a whole body approach in understanding the disease and looking for subtle changes outside the brain, which may be easier to understand than just focusing on the brain. This shift is now seen in Alzheimer's and Parkinson's diseases as the approach to studying these diseases is looking at the whole body.</p>
<p>4) Fund globally recognized excellent HD research</p>	<p>Be the funder of choice for HD research.</p> <ul style="list-style-type: none"> <li>• Continue to build HD research critical mass.</li> </ul>	<p><b>2014 – 2015</b>  5 Human clinical trials launched, first human trials addressing the root cause of HD in history HSC launched a user friendly map locator for families HSC invited global thought leaders in HD research to a round table discussion to ask how we should spend a million in order to have the most impact on the global understanding of treatments for HD. Subsequent to the meeting, Brain Canada agreed to match the donor investment resulting in incremental 2 million invested in HD research. The HD Consortium finalized the HD specific Clinical Trials Readiness Checklist to help clinicians get involved in HD research, published the HD Best Practices Guide with the input of researchers, clinicians and families - a first in Canada</p> <p><b>2016</b>  The first recipient, of the HSC-Brain Canada Grant, was announced – Dr. Simonetta Sipione from the University of Alberta  HD Consortium published the HD National Clinical Trial Recruitment strategy</p> <p><b>2017</b>  The second recipient, of the HSC-Brain Canada Grant, was announced – Dr. Blair Leavitt from the University of British Columbia  Recipients the 2017 Navigator Research Awards are announced:  Dr. Stephen Ferguson, University of Western Ontario: <i>mGluR5 as a target for the treatment of Huntington disease</i>  Dr. Lynn Raymond, University of British Columbia: <i>Impaired corticostriatal synaptic plasticity in HD: Investigating a role for aberrant endocannabinoid signaling</i>  Dr. Matthew Parsons, Memorial University of Newfoundland: <i>Probing Novel Therapeutic Targets for the Treatment of Cognitive Decline in HD</i></p>

<p>5) Increase the awareness of HD</p>	<ul style="list-style-type: none"> <li>• Increase awareness of HSC within HD community and families impacted by HD that currently do not affiliate themselves with HSC.</li> <li>• Increase awareness outside of the HD community.</li> </ul>	<p><b>2013</b> Do You Really Want to Know? PSA is published, in partnership with the producers of the documentary on Huntington disease.</p> <p><b>2015</b> #LightItUp4HD is launched with the lighting of the CN Tower in Toronto with blue for HD and purple for Juvenile HD</p> <p><b>2016</b> #LightItUp4HD expands to include Spain, US, Ireland, Scotland and the UK What is HD? PSA is published using HD community volunteers to tell their personal stories Barb's Ribbon's of Hope launches</p> <p><b>2017</b> #LightItUp4HD expands to include Australia, Cypress, Germany Huntington disease: global humanitarian event, the meeting of HD families from Latin America and from all over the world with Pope Francis - Vatican City, May 18, 2017</p>
<p>6) Inspire engagement and collaboration with internal and external stakeholders</p>	<ul style="list-style-type: none"> <li>• Maximize our connection with HD families and individuals</li> <li>• Create opportunities for stakeholders and interested parties to become involved in the society.</li> <li>• Leverage current stakeholder relationships to foster new stakeholder relationships.</li> </ul>	<p><b>2012 -2013</b> Grand River Chapter (KW area), Kingston/Belleville Chapters established</p> <p><b>2016</b> The 2016 National Conference was hosted in Halifax, Nova Scotia HSC partners with Clinical Trials Ontario and N2 to present an HD clinical trial national webinar</p> <p><b>2015 -2017</b> HSC partners with N2, the Networks of Networks and Clinical Trials Ontario to streamline efforts to bring clinical trials to Canada. HD Consortium continues to meet on a regular basis moving the National HD Clinical Trial Strategy forward</p>
<p>7) Ensure financial and organizational stability and excellence</p>	<ul style="list-style-type: none"> <li>• Achieve revenue growth goals.</li> <li>• Enhance financial and organizational processes to build efficiencies and manage risk.</li> <li>• Improve processes to meet internal and external financial reporting requirements.</li> <li>• Sustain and nurture a high performing team.</li> </ul>	<p>HSC consistently meets revenue goals</p> <p><b>2012</b> Full review of financial processes completed, upgraded, efficiencies implemented. An employee survey was implemented on an annual basis to bench mark how employees are engaged with the mission of the organization. Consistent results identified that 100% of employees understand how they contribute to the mission of the organization. HSC consistently posts annual report and annual financial statements on website</p>