



**2014 – 2015 Pre-Budget Consultation
Submission to the Standing Committee on Finance**

August 6th, 2014

Executive Summary and Recommendations

Crohn's and Colitis Canada is pleased to provide input to the Standing Committee on Finance for its 2014-2015 pre-budget consultation. Our perspective is that of the estimated 1 million Canadians who are affected by Crohn's disease and ulcerative colitis, including the 233,000 who live with these diseases, their families and caregivers.

Canadians have more reasons to be concerned about Crohn's and colitis than anyone else in the world. One in every 150 Canadians suffers from Crohn's and colitis, a rate that ranks in the highest worldwide. Sadly, there is also a sharp increase in the incidence of children under the age of 10. Families new to Canada are developing Crohn's and colitis for the first time – often within the first generation. These are 'Canada's chronic conditions.'

The recommendations from Crohn's and Colitis Canada are targeted in addressing the theme of supporting families and helping vulnerable Canadians by focusing on health, education and training.

Recommendation 1: Recognize Crohn's disease and ulcerative colitis within government health bodies and the Public Health Agency of Canada (PHAC). Specifically, list Crohn's disease and ulcerative colitis on the list of identified chronic conditions. Also, increase CIHR funding towards cure-related and epidemiological research for Crohn's disease and ulcerative colitis.

Recommendation 2: Ensure comprehensive drug coverage so that all Canadians have access to approved medications regardless of their ability to pay.

Recommendation 3: Increase the Employment Insurance Compassionate Care Benefit period from six to a minimum of 26 weeks and extend eligibility to caregivers who are providing support to those living with a serious chronic or episodic medical condition.

1. Increased recognition of Crohn's disease and ulcerative colitis

Crohn's disease and ulcerative colitis are lifelong chronic diseases without cures or known causes. With nearly a quarter million Canadians living with Crohn's and ulcerative colitis, these diseases together costs Canadians more than \$2.8 billion each year in direct and indirect expenses. People living with Crohn's disease are 47 % more likely to die prematurely than people living without Crohn's. If left untreated, a person living with Crohn's or ulcerative colitis has an increased risk for developing colorectal cancer. Despite these alarming statistics, Crohn's and colitis are conditions that receive very little attention.

The Public Health Agency of Canada is an important health care agency that focuses on chronic disease and prevention. The website <http://www.phac-aspc.gc.ca/cd-mc/> lists numerous chronic conditions but unfortunately does not list Crohn's or colitis. We wish for Crohn's and colitis to be given due recognition and listed on the website.

The burden that Crohn's and ulcerative colitis places on individuals, the healthcare system and society is significant and will continue to grow as the number of patients with these diseases increases. Crohn's and Colitis Canada calls upon the federal government, through CIHR, to increase its funding towards cure-related and epidemiological inflammatory bowel disease research. We also call on greater investment in IBD research strategies that will expedite translation of academic-based research discoveries into clinical application in humans.

Canada is where advancements in Crohn's and colitis treatments and research are taking place. Canada is a leader in discovery research and has created centres of excellence in patient care because of its highly talented and skilled gastrointestinal medical and research community. This is home to where discovery research has led to the development of a new treatment that will lead to longer periods of remission. Canada is also where groundbreaking research work is currently being conducted to identify the genetic, microbial and environmental (GEM) factors that determine the causes of Crohn's disease. The GEM project follows high-risk Canadian patients before and after diagnosis. These projects and the commercialization of treatments are funded by foreign and external donors, to a large extent. Crohn's and Colitis Canada seeks greater domestic recognition and funding support. Despite the high rates of incidence, many Canadians are still unaware of these diseases and the symptoms associated to the condition, such as the urgent need for washroom access.

Recommendations:

- Add Crohn's and colitis onto the PHAC website list of identified chronic conditions.
- Increase CIHR funding towards cure-related and epidemiological research for Crohn's disease and ulcerative colitis.

2. Comprehensive Drug Coverage

Comprehensive drug coverage remains an issue of concern for Crohn's and Colitis Canada given the number of inequities of accessing inflammatory bowel disease treatments across the country. The provinces cover different medications at different costs, many Canadians living with Crohn's and colitis do not have access to private health insurance or are ineligible for government drug benefit plans, and the costs of prescription drugs are prohibitive for many.

In a 2011 national online survey that explored the physical, social and economic impacts of living with Crohn's and colitis, drug coverage was a concern for the majority of the 430 participants. Though 66% of survey respondents said they have drug coverage through an employer or school, 24% of that group said they were denied insurance coverage for medications needed to manage their IBD. Approximately 19% of survey respondents relied on provincial and territorial drug programs and nearly 8% had no drug coverage at all. A quarter of the total number of survey respondents have admitted to borrowing money to pay for their vital IBD medications. Furthermore, according to the 2013 Health Care in Canada Survey, 76% of Canadians felt that governments should establish a maximum limit to how much individuals should have to personally pay out of pocket for prescribed medications.ⁱ

Advocating for improved access to treatments continues to be a priority issue at Crohn's and Colitis Canada. Over the past year, Crohn's and Colitis Canada has participated in numerous drug approval consultations federally and provincially and as a result of these discussions, we call on the federal government to develop consistency and a standard of treatment and care across Canada to ensure that all Canadians have access to approved medications regardless of their ability to pay.

Recommendations:

- Ensure that all Canadians should have access to comprehensive drug coverage (either through public or private plans) regardless of their ability to pay or where the drug is given.
- Implement standards to see that charges to the patient are limited to ensure equitable access to prescription medications.

- Encourage the establishment of a pan-Canadian income-based ceiling on out-of-pocket expenditures on drug premiums and/or prescription drugs.
- Develop a common, national minimum drug formulary should be created to provide greater consistence and to drive savings within the system.

3. Supporting Caregivers

Everyone at some point in their life will be a caregiver. For many affected by Crohn's disease and ulcerative colitis this is a current reality. Caring comes with challenges. Absences from work, high costs of care and fatigue and stress can generate negative emotional and mental health.

With increasing numbers of children being diagnosed with Crohn's disease and ulcerative colitis, parents play an important caregiver role. Based on the Impact of Inflammatory Bowel Disease (IBD) Report, the caregiver costs for parents of children living with Crohn's and colitis totalled \$7 million for the estimated 5,900 children living with IBD in Canada in 2012. Potentially, the overall cost of caregiving for people living with severe forms of Crohn's disease and ulcerative colitis is estimated to be at \$86 million annually.ⁱⁱ

Crohn's and Colitis Canada recognizes some of the positive initiatives that have helped to alleviate the pressures of caregiving. For example, extending the Family Caregiver Tax Credit provides caregivers with tax relief. However, more needs to be done to alleviate the burden faced by caregivers. Crohn's and Colitis Canada calls on the federal government to expand the Employment Insurance Compassionate Care Benefit to extend eligibility to caregivers who provide support to those living with a chronic or episodic medical condition. Currently eligibility is limited to only caregivers who are caring for loved ones who are at risk of death within 26 weeks. Providing flexible benefits will allow for caregivers to balance employment with their caregiving role.

Recommendations:

- Address the needs of caregivers by expanding the Employment Insurance Compassionate Care Benefit:
 - extend eligibility to caregivers who provide support to those living with a chronic or episodic medical condition; and
 - increase the benefit period from six to a minimum of 26 weeks.



About Crohn's and Colitis Canada

www.crohnsandcolitis.ca

Crohn's and Colitis Canada is a volunteer-based national charity dedicated to find the cures for Crohn's disease and ulcerative colitis and to improve the lives of children and adults affected by these chronic conditions. Our organization delivers on its promise by investing in research, education and awareness. Crohn's and Colitis Canada is Canada's top non-governmental funder of cure-directed research and is a world leader in funding per capita of such research.

Crohn's and Colitis Canada is comprised of approximately 65,000 supporters including volunteers, donors or individuals interested in engaging with the organization. Currently there are 45 large community-based networks and 24 small community groups across Canada. Crohn's and Colitis Canada is governed by a Board of Directors and is further supported by committees, groups and advisory councils.

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ⁱ Health Care in Canada. "A national survey of health care providers, managers and the public". 2013.

ⁱⁱ Crohn's and Colitis Canada, "The Impact of Inflammatory Bowel Disease in Canada 2012 Final Report and Recommendations", 59. 2012.