

## The Burden of IBD in Canada

### About Inflammatory Bowel Disease (IBD)

- IBD is a group of disorders that cause the intestines to become inflamed and ulcerated. This is caused by an abnormal response of the body's immune system.
- The main forms of IBD are Crohn's disease (CD) and ulcerative colitis (UC).
- There is no cure for IBD; therapy is directed at achieving and maintaining freedom from symptoms. Most people require ongoing medication; when this fails, surgery is often required.
- IBD is a lifelong disease, usually starting in early adulthood in otherwise healthy, active individuals.
- IBD imposes a significant impact on quality of life through ongoing symptoms, reduced ability to work, social stigma, management of toilet access issues, difficulty with physical intimacy and restriction in career choices.
- Medical research is simply the best hope for finding a cure for Crohn's disease and ulcerative colitis known collectively as inflammatory bowel disease (IBD).

### IBD in Canada

- There are more than 200,000 Canadians living with IBD: 112,000 with CD and 88,500 with UC. One in every 160 Canadians has IBD.
- Over 9,200 new cases are diagnosed every year – 5,100 with CD and 4,100 with UC.
- Canada has among the highest reported prevalence (number of people with CD or UC) and incidence (number of new cases per year) of IBD in the world.
- IBD can be diagnosed at any age, but has a typical age of onset in the twenties.
- People with CD and UC have elevated risk of developing colorectal cancer.
- People with CD face a significantly elevated risk of premature death (47% higher) than the general public.

### Comparisons

- IBD is about three times more common than multiple sclerosis or HIV; about as common as epilepsy; and somewhat less common than schizophrenia or rheumatoid arthritis.
- Compared to the general population, quality of life in IBD is low across all dimensions of health; even people with normalized symptoms have a quality of life below average, due to fears and concerns about disease progression.

### Economic Costs of IBD

- Economic costs for IBD are conservatively estimated at \$1.8 billion per year in Canada in 2008 (over \$9,000 per person with IBD every year). Direct medical costs totaled over \$700 million per year. They are dominated by hospitalizations (\$345 million), followed by medications (\$162 million) and physician visits (\$134 million). Costs are higher for CD than

- for UC, due to more frequent hospitalizations and greater use of newer, expensive drugs.
- Indirect costs (to society and to the patient, including loss of productivity) are greater than direct medical costs: over \$1 billion per year. Indirect costs are dominated by lower labour participation rates (long term work loss: \$746 million per year), followed by patient out of pocket expenses (\$239 million) and then short-term work absences (\$138 million). These costs are similar between CD and UC.

### **Areas of greatest challenge**

- There are many challenges for people with IBD in the current environment, ranging from lack of awareness of IBD as a chronic disease, to social stigma, to lack of equity in access to expensive medications:
  - Awareness of IBD – as a chronic disease with unnecessary social stigma
  - Diagnosis of IBD – including late diagnosis and inappropriate diagnosis
  - Access to IBD specialists and procedures – patients face regional disparities in access to care
  - Access to IBD medications – these costs can be prohibitive, but funding is inequitable across the country
  - Employment issues – IBD employees are vulnerable due to their youth and lack of seniority for employment protection
  - Support for people with IBD and their caregivers – there is an absence of community-based delivery of support, particularly for parents
  - Research, ongoing monitoring and evaluation – into the “cause, care and cure” of IBD, and to improve estimates of prevalence and costs

### **Recommendations for a National Vision**

- The CCFC recommends a long-term national vision for the future, to include government, media and the general public. The goals are to change community perceptions and attitudes to IBD, reduce stigma and recognize IBD as a chronic disease within federal/provincial/territorial chronic disease strategies/frameworks.

### **About the CCFC**

- The Crohn’s and Colitis Foundation of Canada (CCFC) is a volunteer-based registered charity, dedicated to finding the cure for Crohn’s disease and ulcerative colitis, commonly referred to as inflammatory bowel disease (IBD). To achieve our mission, the Foundation is committed to raising funds for medical research.
- Medical research is the best hope for finding a cure for Crohn’s disease and ulcerative colitis.
- To date, CCFC has invested \$71 million in major medical research projects and is one of the world’s leading sources of non-governmental funding of IBD research.

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For more information about the Crohn’s and Colitis Foundation of Canada, or to make a donation, please contact:  
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