



November 2, 2009

**Crohn's and Colitis Foundation of Canada Announces Paediatric IBD Initiative
during Crohn's and Colitis Awareness Month**

This November, the Crohn's and Colitis Foundation of Canada (CCFC) is announcing an initiative to gain a better understanding of Crohn's disease and ulcerative colitis among children and adolescents in Canada.

Working with a planning committee of paediatric gastroenterologists across Canada, CCFC will facilitate the work of this group and partners to develop a new way to track paediatric inflammatory bowel disease (IBD) cases at sites across the country.

The initial phase will start with a limited group of hospitals and will focus on how proteins and genes factor into the disease, and factor in the course of the disease through treatment. Building on a successful initial phase, an expanded network will be able to address questions such as how children develop IBD, how they fare with the diseases, and which ethnic groups are seeing steeper rises in youth IBD.

CCFC's paediatric initiative builds on the existing work of Canadian paediatric IBD clinicians and researchers by encouraging and funding research proposals that ultimately would lead to improved quality of care and clinical outcomes for youth with IBD. In its report released in November 2008 titled "*The Burden of IBD in Canada*," CCFC identified the lack of solid data on paediatric IBD rates in Canada as a barrier to validating the epidemiological observation that the incidence of IBD is on the rise amongst children.

The announcement from CCFC coincides with the kick-off of November as Crohn's and Colitis Awareness Month in Canada. Canada has among the highest rates of Crohn's disease and ulcerative colitis in the world and throughout the month of November, CCFC will celebrate the courage of more than 200,000 Canadian men, women and children living with these

debilitating diseases through the announcement of the “Gutsiest Canadian” contest and by hosting Educational Symposiums from coast-to-coast.

This new initiative also complements CCFC’s ongoing investment in the GEM Project, examining the genetic, environmental and microbial factors affecting Crohn’s disease. While the new paediatric initiative will recruit and follow diagnosed children, GEM Project subjects are healthy relatives of persons with Crohn’s disease.

To date, more than 40 per cent of the subjects in the GEM Project are under 18 years of age. By following the healthy siblings, parents or offspring of people with Crohn's Disease who are at greater risk of developing Crohn’s disease over time, the study hopes to understand the complex genetic, environmental and microbial interactions within our own bodies that trigger the illness. GEM Project results will serve to inform CCFC’s paediatric initiative as it develops.

Paediatric IBD Incidence Rates Alarmingly High

“A new study released by Dr. Eric Benchimol in August of this year reveals that paediatric IBD incidence rates in Ontario are alarmingly high,” said Dr. George Tolomiczenko, CCFC’s Director of Research.

“This study and another in British Columbia indicate that immigration is likely a contributing factor, and specifically that the East Indian population in Canada is experiencing paediatric IBD at a rate far greater than their relatives in India and the general population of Canada. The variability in IBD incidence rates together with the ethnic differences between provinces puts Canada in a strong position to examine IBD among children.”

The study "*Increasing incidence of paediatric inflammatory bowel disease in Ontario, Canada: evidence from health administrative data*," was published on the website of the journal *Gut* (gut.bmj.com).

Crohn's & Colitis: Common Diseases, Few Speak about Them

Crohn's disease and ulcerative colitis are two similar, yet distinct, conditions which directly affect the digestive system and cause intestinal tissue to become inflamed, form sores and bleed easily. There is no cure, no known cause, and little public understanding of the pain and chronic suffering which IBD patients courageously cope with every day of their lives.

"It is imperative for us to support the medical research required to find a cure for IBD," says Dr. Kevin Glasgow, Chief Executive Officer of the CCFC. "Canada is home to many of the world leaders in IBD research, and IBD affects millions world-wide."

Facts about IBD

- Crohn's disease and ulcerative colitis are the two most common forms of IBD.
- Patients suffer from symptoms including abdominal pain, cramping, fatigue and diarrhea.
- Most people are diagnosed by the age of 30, and many will experience periods of remission and flare-ups, often requiring long-term medication, hospitalization or surgery.
- The main difference between Crohn's disease and ulcerative colitis is that Crohn's can affect any part of the gastrointestinal tract, from the mouth to the anus, causing patches of inflammation. Colitis affects only the inner layer of the colon, or large bowel, and always starts in the rectum causing continuous inflammation which may spread into the rest of the colon.
- Crohn's disease cannot be cured by drugs or surgery, although both can help relieve symptoms.
- Ulcerative colitis can be completely eliminated by surgically removing parts of the colon, but after surgery waste materials may have to be stored and expelled through an external appliance such as a colostomy bag.
- Afflicting more than 200,000 Canadians, IBD is more common than Multiple Sclerosis or HIV and about as common as Epilepsy or Type 1 Diabetes. The average per-person cost in Canada is more than \$9,000 per year and there are no known causes or cures.
- Using conservative estimates, there are about 3,300 youth under 20 with Crohn's disease and 1,600 youth under 20 with ulcerative colitis in Canada, for a total of 4,900

youth. Application of Dr. Benchimol's methodology in other provinces using administrative health record data would likely generate similarly disconcertingly higher – and more accurate – estimates.

Facts about CCFC

- The Crohn's and Colitis Foundation of Canada (CCFC) is a voluntary, not-for-profit, medical research foundation dedicated to finding the cure for Crohn's disease and ulcerative colitis. The Foundation is committed to educating IBD patients, their families, health professionals and the general public about the diseases.
- Since its founding, CCFC has invested more than \$61 million in a diverse portfolio of research projects, making the foundation a world leader in non-governmental funding of IBD research.
- Canadian researchers funded by CCFC are conducting cutting edge research and are sustaining the hope for a cure worldwide.
- In 2003, CCFC founded the IBD Research Institute (IBDRI) to advise the Foundation on national and international IBD research projects and researchers. The IBDRI is currently funding 70 research grants, projects and scientist awards.

For more information about the CCFC, please visit [.ccfc.ca](http://ccfc.ca), for more information on the GEM Project, please visit [.gemproject.ca](http://gemproject.ca) and for more information on Crohn's and Colitis Awareness month, please visit [.getgutsymonth.com](http://getgutsymonth.com).

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In addition to CCFC's professional staff, CCFC has committed volunteers and members across Canada who would be willing to speak with media about their experience with IBD. If you would like to speak with one of our volunteers, or for more information, please contact Allison Lawrence or Adriana Lurz at Strategic Objectives.

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