



Crohn's and Colitis
Foundation of Canada

Fondation canadienne des
maladies inflammatoires
de l'intestin

CCFC & *You*

Tapping Patient Experience for experiential insight

**IHE Symposium on Patient Involvement in HTA, Feb. 5th, 2010
George Tolomiczenko, Executive Director of Research &
Scientific Liaison**



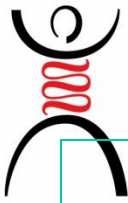
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Discussion topics

- IBD
- Canadian Crohn's and Colitis Foundation
- Patient experiential journeys
- From peer-to-peer to payor policy



What is IBD?

- IBD – Inflammatory Bowel Disease
- A group of chronic disorders that cause the intestines to become inflamed and ulcerated
- Includes:



Crohn's/Crohn Disease
(named after Dr. Burrill B. Crohn)
&
Ulcerative Colitis

- Does not include: IBS – Irritable Bowel Syndrome



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What is Crohn's Disease?

- Chronic inflammatory disease of the gastrointestinal tract
- Believed to develop as a result of the stimulation of a dysfunctional immune response in genetically susceptible individuals
- Can occur anywhere in the GI tract from the mouth to the anus
 - 45% - terminal ileum and beginning of colon
 - 35% - terminal ileum only
 - 20% - colon only



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What is Ulcerative Colitis?

- Ulcerative colitis attacks the inner lining of the large bowel (colon) with inflammation, ulceration, bleeding and scarring.
 - 30% - rectum +/- sigmoid colon
 - 40% - 1/2-2/3 of left half of colon
 - 30% - entire colon
- Looks a lot like scraped skin in a continuous pattern



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Symptoms of Crohn's Disease & Ulcerative Colitis

- Diarrhea
- Abdominal pain
- Blood loss/anemia
- Weight loss
- Weakness
- Fatigue
- Nausea/vomiting
- Fever



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The Burden of IBD in Canada

CCFC Report presented 2008 findings:

- Canada has among the highest reported prevalence & incidence of IBD in the world
- Nearly **201,000** Canadians with IBD
 - 112,000 with Crohn's disease
 - 88,500 with Ulcerative Colitis
- Over 9,200 new cases diagnosed every year
- Higher rates in urban areas vs. rural areas

Copies of the full report available via CCFC website



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The Burden of IBD in Canada

Comparisons

- IBD is 3x more common than MS or HIV
- As common as Type I diabetes or epilepsy
- Compared to general population – lower quality of life



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The Burden of IBD in Canada

- **Direct medical costs - \$700 Million/year**
 - Hospitalizations - \$345 million/year
 - Medications - \$162 million/year
 - Physician visits - \$134 million/year
- **Indirect Costs - \$1.1 Billion/year**
 - Long term work loss - \$746 million/year
 - Patient out-of-pocket expenses - \$239 million/year
 - Short term work absences - \$138 million/year



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- Established in 1974 by a group of parents
- The Crohn's and Colitis Foundation of Canada is a national, voluntary, not-for-profit, medical research Foundation dedicated to finding the cure for Crohn's disease and ulcerative colitis, diseases commonly referred to as inflammatory bowel disease.
- To achieve its Mission, the Foundation is committed to raising funds for medical research.
- Raising awareness of IBD
- Currently 65,000 supporters, 75 local volunteer Chapters, Chapters-in-Development and Affiliates nationwide
- Volunteer driven



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Vision of the CCFC

- The CCFC believes that a cure will be found for Crohn's disease and ulcerative colitis. To realize this, the CCFC is committed, first and foremost, to raise increasing funds for medical research.
- The CCFC also believes it is important to make all individuals with IBD aware of the Foundation, and educate these individuals, their families, health professionals and the general public about these diseases.



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Values of the CCFC

- The greatest proportion of funds raised must be allocated to research;
- Collaboration with the medical community is imperative;
- Goals must be set and met throughout the organization;
- Participation by volunteers is crucial to our success;
- The success of the Foundation rests on the mutual respect of staff and volunteers;
- The national nature of the Foundation must be respected;
- All volunteers, members, supporters and employees have a right to contribute in an environment that asserts the personal worth and dignity of each individual.



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- Created to recruit volunteers in areas that require more volunteers to provide residents in those communities with the resources they need.
- Looking to recruit enthusiastic women and men of all ages who will make an ongoing time commitment.
- Be a part of finding the cure! Join the Crohn's and Colitis Foundation of Canada's XXX Chapter team of valued volunteers – "Our Heart & Our Soul".



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Categorization of CCFC Funded Research 2004-2008

•Immunology/Immunoregulation

- study of cell mediated immune response and regulation in IBD

•Gut

- study of processes at the gut wall

•Genetics

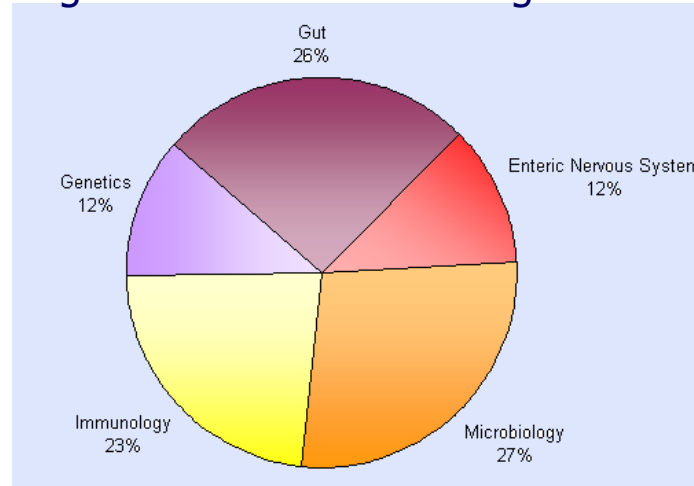
- identification of susceptible genes and understanding their function

•Microbiology

- study of bacteria and intestinal flora with respect to IBD

•Enteric Nervous System

- study of nerves, neurons and their interactions in IBD patients





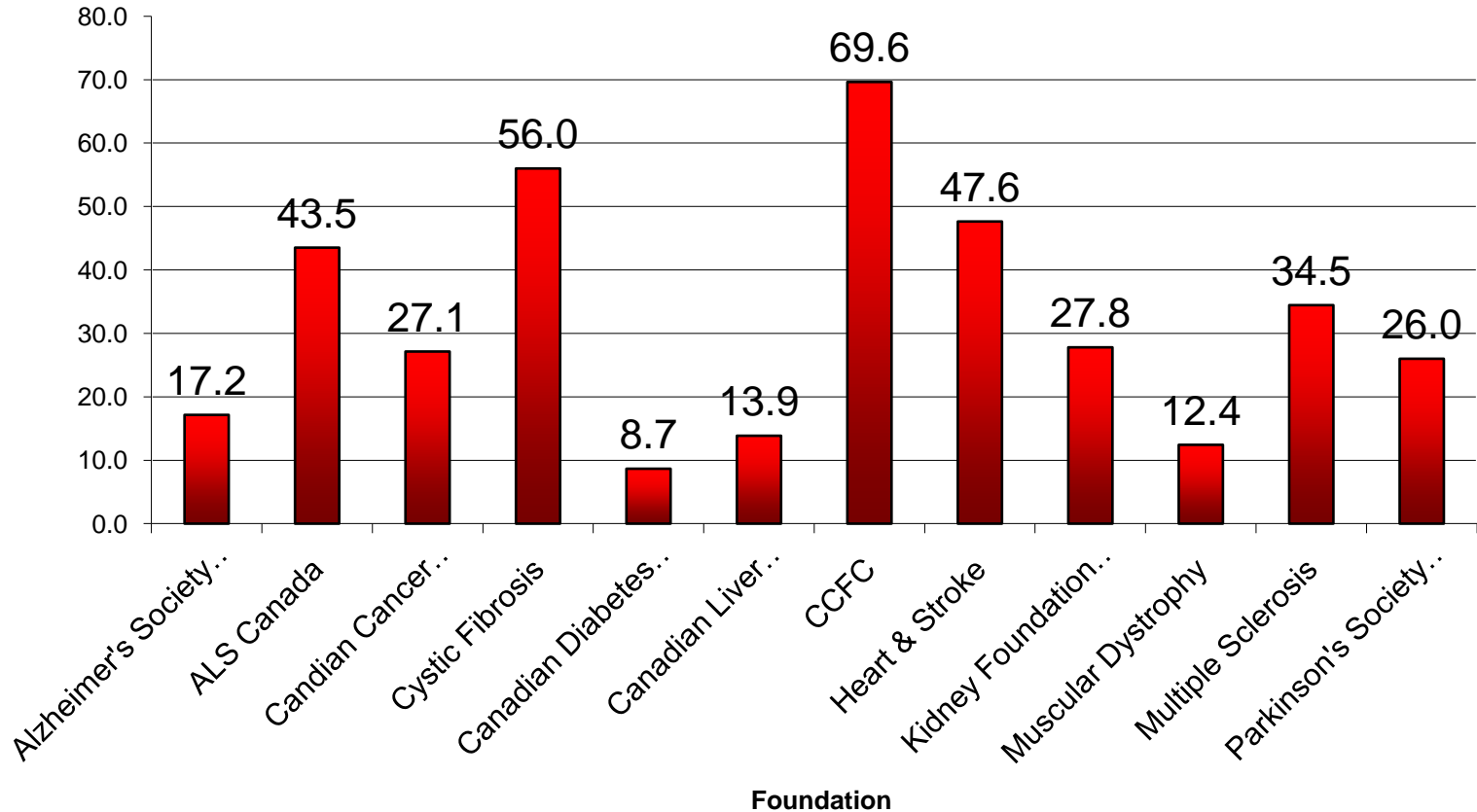
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Balancing Research & Support

Percentage of Revenue Spent on
Research





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Patient's Journey Stage 1: Living with symptoms before diagnosis

- Bowel symptoms
- Systemic symptoms
- Emotional status
- Social impact
- Sexuality & Fertility
- Vocational functioning



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Patient's Journey Stage 2: Living with symptoms during diagnosis

- Diagnostic errors common
- Lack of Awareness among primary care physicians
- Lengthy wait times for specialists
- In some cases, technology needed to make a definitive diagnosis is not available
- Start treatment at different stages of disease process which also likely varies considerably between cases



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Patient's Journey Stage 3a: Treatment for IBD

- Diet
- Medication
 - Anti-inflammatories (not as effective for small bowel CD) – used for mild to moderate disease
 - Steroids (significant side effects)
 - Immunosuppressants
 - Antibiotics
 - Biologics
- Surgery





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Patient's Journey Stage 3b: Living with IBD

- See stage 1 and add:
 - Financial impact
 - Insurance



Choice of the most expensive treatment option: Biologics

- "...used for people with moderately-to-severely active disease who have not responded well to other therapies."
- "...used for people with moderately to severely active disease who have not responded well to other therapies, and who have lost response or are unable to tolerate (another biologic)."
- "...used to reduce the signs and symptoms of moderately to severely active Crohn's disease in adult patients who have not been helped enough by usual treatments."
- "...for moderate to severely active Crohn's patients who have had an inadequate response to, or are unable to tolerate, conventional and anti-TNF disease therapies."



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Patient's Journey Stage 4: Peer-to-Peer support

High risk of effects of TMI (Too much Information):

- Websites:
 - General Health/Disease portals
 - Disease-specific sites
- Social Networking groups
 - Allow for anonymous, self-organized and time limited support groups
 - Particularly appealing to and utilized by younger people



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Top 10 Tips for people with IBD (no particular order)

- Learn about IBD, its signs and symptoms: Ask lots of questions.
- Remember that everyone with IBD is different.
- Find someone you can talk to about your condition who will lend a sympathetic ear.
- Eat a well-balanced diet and supplement with vitamins as needed.
- Don't do more or less than you would if you didn't have either CD or UC.
- Ask your healthcare provider about your medications.
- Follow-through with medications and treatments.
- Some medications need to be continued even when you are well.
- Don't smoke – especially if you have CD.
- If you have UC, have regular colonoscopies.

(Prepared for WGO by Drs. Charles Bernstein & Hillary Steinhart)

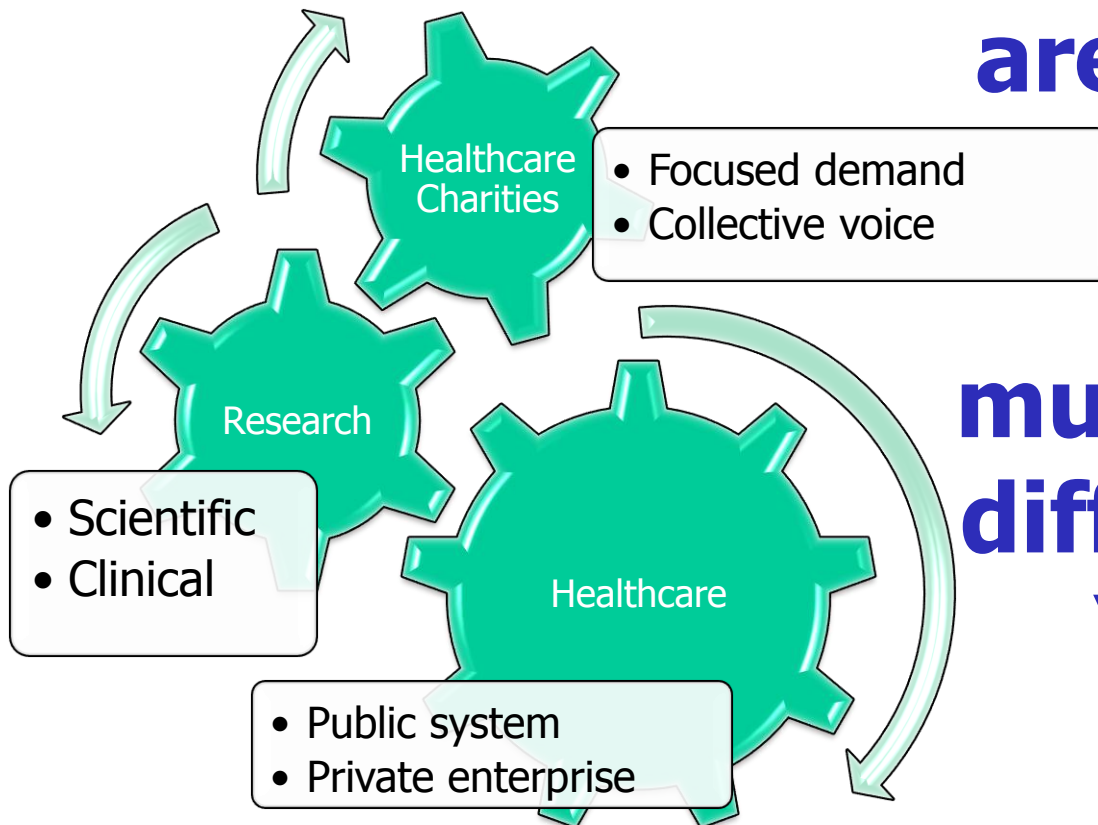


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Patient journeys and experience are affected by



multiple cogs in different health "systems"



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From P2P to Payor Policy

- Response to CADTH's request for feedback:
 - More time
 - Maintaining some level of pharma support without losing voice
 - Work with us to develop gathering and updating patient input relevant to "comparative effectiveness"
 - Value of combining patient input with professional input
 - Guidance on specific aspects of patient experience relevant to the new drug being evaluated



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CCFC is looking forward to learning more about these issues with you!

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