INTRODUCTION

The Crohn’s and Colitis Foundation of Canada (CCFC) (previously the Canadian Foundation for Ileitis and Colitis – CFIC) supports medical research in inflammatory bowel disease (IBD), undertakes education of physicians and patients, and advocates support for some specific needs of patients with IBD. The Foundation has a Lay Board and a Medical Advisory Board (MAB). The Lay Board is involved in the administration of the Foundation and in organizing drives to obtain charitable donations. The MAB has three major committees: the Research Committee, the Education Committee and the Patient Advocacy Committee. The Research Committee reviews research applications and advises the Lay Board on the distribution of funds to support research. The Education Committee provides educational material for patients and physicians.

Issues of concern to patients with IBD range from provincial funding of costly drugs and nutrients, the availability of insurance benefits for persons with IBD, to the human rights of persons suffering from IBD. Because of this a Patient Advocacy Committee was established in 1986. This Committee was charged to establish representations to Provincial Governments, to approach the insurance industry and to deal with other relevant issues. The first chairman of this new committee was Dr Edward Prokipchuk. During his chairmanship the committee was able to get approval for total parenteral
nutrition, and the inclusion of some liquid nutrients into the drug lists of several provinces. At the 20 September, 1991, meeting of the Medical Advisory Board, the second chair of this committee, Dr Suzanne Lemire, presented a report addressing the problems being faced by those with IBD seeking life insurance coverage. Examples of the current rating methods based on the 1985 edition of Brackenridge's text on life risks suggested that there may be a great deficiency in the data upon which such rating is based, and thus it appeared that most of the data used were outdated.

A book written in 1985 could not have included morbidity and mortality data published after 1982. Any report published in 1982 would deal with cases that were collected during the 1970s. Because of the improved diagnostic techniques, improved medical and nutritional support, and safer and less complex surgery in the 1980s, the MAB of the CCFC assumed that the mortality and morbidity figures must have improved since the publication of Brackenridge's text.

Therefore, the MAB of the CCFC decided to organize a conference to review recent data on the morbidity and mortality of IBD. An Organizing Committee consisted of Drs Ivan T. Beck, Kingston (Chair); Desmond J. Leddin, Halifax; Suzanne E. Lemire, Quebec; Eldon A. Shaffer, Calgary; Lloyd R. Sutherland, Calgary and Alan B. R. Thomson, Edmonton. The meeting was fully supported by the Lay Board, and Mr Raymond J. van Berkel, Executive Director of the CFIC from Toronto, was made an ex-officio member of the Organizing Committee. The Lay Board was also represented at the Conference by Dr Ted Hannah, Liaison Chairman of the Lay Board to the Medical Advisory Board. The advice of Dr Guy Tremblay, Past-President, Canadian Life Insurance Medical Officers Association, was obtained at the first meeting of this committee.

Because the CFIC is a charitable organization there were only limited funds available to arrange this meeting; therefore the Organizing Committee decided to hold the conference in combination with a major symposium on IBD. This allowed us to draw on the expertise of some of the well-known international investigators who attended the other meeting. Starting with a reception on the evening of 20 May 1992, the Falk Symposium on ‘Trends in Inflammatory Bowel Disease Therapy’ was held in Quebec-City between 21 and 23 May. The CCFC was fortunate to be able to organize its conference on morbidity and mortality during the day of 20 May 1992. This is how we could attract Dr Richard Farmer (previously from the Cleveland Clinic, presently the Medical Advisor to the Agency of International Development, Washington, DC, USA); Dr Goran Hellers (from the Department of Surgery, Karolinska Institute, Huddinge University Hospital, Huddinge, Sweden); and Vibeke Binder (from the Medical Gastroenterology Department of Herlev Hospital, University of Copenhagen, Herlev, Denmark). In addition to these speakers we were fortunate to have Rod Riley from the Canadian Centre for Health Information, Statistics Canada, to talk on the Canadian experience on morbidity and mortality of Crohn's disease and ulcerative colitis. Most importantly we had to find an outstanding clinician, who has in-depth knowledge of insurance matters, and who could interact with the speakers and the audience. Dr Guy Tremblay, an academic cardiologist and