

## A Closer Look at the European Crohn's and Colitis Organization

a report by

**Geert D'Haens and Walter Reinisch**

*Director, GI Clinical Research Center, Imelda Hospital, and  
Department of Internal Medicine, University of Vienna*

Geert D'Haens is Director of the GI Clinical Research Center at Imelda Hospital, where he also works in the Gastroenterology Department.

He is also a consultant gastroenterologist for inflammatory bowel disease (IBD) in the Section of Gastroenterology and Endoscopy at the University Hospital Gasthuisberg and a consultant for several pharmaceutical companies.

Dr D'Haens is a member of the Medical Ethical Committee of Imelda Hospital, a board member of the

Vlaamse Vereniging voor Gastroenterologie (VVG), President of the Belgian IBD research club, a member of the American

Gastroenterological Association (AGA), a member of the European

Society for Gastrointestinal Endoscopy (ESGE) Research Committee, a Secretary of the

European Crohn's and Colitis Organization (ECCO), part of the Christian democratic think-tank Man and Society (CEDER) and a member

of the International Organization for Inflammatory Bowel Disease (IOIBD). His main interests are in

the fields of IBD, mucosal immunology, gastrointestinal (GI) endoscopy and immunosuppression.

Dr D'Haens has served as a reviewer for *Gastroenterology*, *Digestive Disease and Sciences*, *Digestion*, *Tijdschr Geneeskunde*,

*American Journal of Gastroenterology*, *Gut*, *The Lancet* and *IBD*. He has been on the editorial board of *IBD* since 2003.

The European Crohn's and Colitis Organization (ECCO) is a non-profit scientific organisation that was founded in Vienna in 2001. Its background was the European idea of international collaboration on the 'old continent'.

Virtually every country in Europe had 'national' or 'regional' study groups interested in the field of inflammatory bowel disease (IBD), including Crohn's disease (CD) and ulcerative colitis (UC). However, the majority of European countries were too small to be able to set up ambitious scientific projects that would result in a significant impact on medical practice.

The first steps towards bringing together several European study groups focused on IBD were taken in Padova in 2000. This is where Dr Renzo Caprilli from Roma and Dr Geert D'Haens from Belgium met at an international meeting and first discussed the idea.

Several opinion leaders from other European countries were contacted and invited to join the organisation with their national group; Dr Walter Reinisch from Austria, Dr Jean-Frédéric Colombel from France representing the prestigious Groupe d'Études Thérapeutiques des Affections Inflammatoires Digestives (GETAID) and Dr Miguel Gassull from Spain representing Grupo Español de Trabajo en Enfermedad de Crohn y Colitis Ulcerosa (GETECCU) were some of the founding members who discussed the first draft of bylaws in Vienna in the spring of 2001. Soon thereafter, several other countries joined, including Switzerland, Sweden, Croatia, Germany, Britain and Israel. Currently, at its fifth anniversary, ECCO counts 24 member countries.

As the umbrella organisation of national IBD groups and/or societies, ECCO wishes to perform and co-ordinate research and education in the field of IBD. The goals of the group are:

- to promote, sponsor and steer European research efforts in the field of IBD and to develop and assist in the development of

protocols for studies to be performed in European centres;

- to organise education and exchange within IBD;
- to develop co-operation with patient organisations and other organisations that share an interest in IBD;
- to establish consensus and challenge dogmas in the field of IBD;
- to have a political voice in Europe and interact with the pharmaceutical industry;
- to educate 'specialist nurses' in IBD;
- to participate in the activities of the United European Gastroenterology Federation (UEGF); and
- to influence the future of IBD management in Europe and beyond.

The daily management of the organisation is the responsibility of the governing board. The current members of this board are Renzo Caprilli, Italy (President); Miguell Gasull, Spain (President-Elect); Geert D'Haens, Belgium (Secretary); Herbert Tilg, Austria (Treasurer); Stefan Schreiber, Germany (Liaison Officer); Boris Vucelic, Croatia (Chairman of the Educational Committee); and Daan Hommes, The Netherlands (Chairman of the Scientific Committee).

Once a year, the general assembly meets, usually during the European United Gastroenterology Week (UEGW) in the autumn. The next meeting will take place in Copenhagen in October 2005. The assembly appoints the governing board, decides on changes in the bylaws and approves the annual budget. The industrial sponsors are all invited to attend. ECCO receives substantial financial support from corporate partners besides national member fees.

This article takes a closer look at what ECCO has accomplished after five years of activities.



# European Crohn's and Colitis Organization

The collaborative scientific organization uniting  
European national IBD study groups

ECCO wishes to perform and coordinate research and education in the field of inflammatory bowel disease (IBD). The goals of the group are therefore as follows:

- ▶ to promote, sponsor and steer European international research efforts in the field of IBD and to develop and help to develop protocols for studies which can be performed in European centres,
- ▶ to organize education and exchange in the field of IBD,
- ▶ to develop cooperation with patient organizations and other organizations sharing interest in IBD,
- ▶ to establish consensus and challenge dogmas in the field of IBD,
- ▶ to have a political voice in Europe and interact with the pharmaceutical industry, to
- ▶ educate 'nurse specialists' in IBD
- ▶ to participate in the activities of the United European Gastroenterology Federation UEGF and in the organization of the annual UEGW, and
- ▶ to influence the future of IBD management in Europe and beyond.

# ECCO

[www.ecco-ibd.org](http://www.ecco-ibd.org)

### Scientific Activities

From the outset, ECCO has declared improvement in European research quality in the field of IBD as its principal goal. It is focused on opportunities and gaps in IBD research, which requires a network of centres of excellence. For initiatives requiring large numbers of patients, international co-operation is almost inevitable. Furthermore, ECCO recognises that research in the field of IBD could be better organised around mission-based goals, necessitating the assembly of experts representing different specialities, such as medicine, surgery, pathology, genetics, cell biology, immunology and epidemiology.

Soon after ECCO's official constitution, the first study proposals were submitted and many more ideas for studies were raised. In addition, the rapid growth of the number of participating countries with their different local regulatory issues and research cultures urged for experts to concentrate specifically on the increasing demand of scientific work. As a result, the establishment of a scientific committee (SciCOM) within ECCO was contemplated by the governing board and proposed to the general assembly by Daan Hommes, who was appointed head of the group during the 2004 UEGW in Prague. Furthermore, a scientific advisory board to the SciCOM was installed. Teamwork is the key to success of SciCOM, as the research endeavour requires that different skills be brought together. Yehuda Chowers (Israel), Walter Reinisch (Austria), Simon Travis (UK) and Severine Vermeire (Belgium) were appointed by the governing board and the head of the SciCOM to join the five-member committee. More recently, ECCO's governing board has considered a further expansion by inviting Reinhold Stockbrügger (The Netherlands), who heads the European Collaborative Study on Inflammatory Bowel Disease (EC-IBD), to step in.

Since 1990, EC-IBD has represented a successful group of clinicians and researchers throughout Europe, addressing clinical epidemiology on IBD in 12 European countries. The merger of ECCO's SciCOM with EC-IBD will be of mutual benefit in the context of further promoting studies in the field of epidemiology and alleviating the economic hurdles in raising funds for population-based studies in Europe. The novel structure of the SciCOM will be proposed to ECCO's general assembly during UEGW in October 2005.

To achieve its ambitious target, the SciCOM made an inventory of all ECCO members, by means of a 'Who's who?' book that was published in April 2005. This handbook, which includes information on the various aspects of European IBD centres – IBD infrastructure, good clinical practice (GCP) facilities, laboratory facilities and endoscopy – was the first

achievement of the SciCOM. It will be of great help for the organisation of scientific projects and, after implementation in ECCO's homepage, for rapid electronic communication between the SciCOM and the centres.<sup>1</sup> Building on its 'Who's who?' book, the SciCOM will also assist the biomedical industry in its selection process of clinical trial centres. The first collaborations in this respect have been initiated. The content of the network will be updated every few years, as centres will enhance their level of research and expertise in the near future.

In accordance with the aims of the SciCOM, the first ECCO Research Fellowship has been launched recently, for which projects had to be submitted before 15 September 2005. From 2006 onwards, the annual deadline for submission for the ECCO Fellowship will be 1 July. Applicants should be aware that these awards are offered to promote and encourage innovative research in IBDs by young and enthusiastic scientists. A total amount of €30,000 will be awarded. Details on the ECCO fellowship are available on the organisation's homepage.

In collaboration with the educational committee of ECCO, the SciCOM developed the programme for 'IBD 2006: The Anniversary Congress of the European Crohn's and Colitis Organisation', representing the first scientific IBD meeting organised by ECCO to be held at the Academic Medical Center of the University of Amsterdam, 8–11 February 2006. The programme intends to give attendees a top-quality, state-of-the-art overview presented in a concise manner with practical recommendations. Integrated in the meeting is ECCO's advanced IBD course. There are plans for further meetings in an expanded format allowing the presentation of results from original scientific work of young European researchers.

### SciCOM Scientific Projects 2005

Currently, ECCO's SciCOM has several on-going scientific projects listed below:

- The Marie Curie programme – the aim of this is to start a pan-European inception cohort of IBD patients and train individual fellows across participating centres.
- Autologous stem cell transplantation in CD – this initiative to explore the possibilities of autologous stem cell transplantation for severe, therapy-resistant CD in a randomised controlled trial has recently received a favourable response by the Broad Foundation. ■

*This article is continued in the Reference Section on the website supporting this business briefing ([www.touchbriefings.com](http://www.touchbriefings.com)).*