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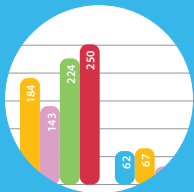
# ECCO

## News **SUMMER**



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and Secretary

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## ECCO NEWS

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# Of ECCO and its spirit

Is ECCO in danger of losing its ECCO Spirit? No. It can't and it won't. The ECCO Spirit is about humanity. It's about the art of medicine, aligned to science. It is quintessentially about the practice of medicine, as applied to the care of our patients with inflammatory bowel disease. Science drives practice – and so it should. Science therefore drives ECCO, but it is at the interface between science and humanity that the spirit of ECCO is found.

**ECCO started just over ten years ago** as a group of people driven to improve the care of patients with IBD. That should (and will!) always remain its mission: improving the care of patients is our *raison d'être*. ECCO started as a confederation of nations, seeking common ground. One outcome, among many, has been a real consensus on practice, captured in its international guidelines, through a process which cannot be matched anywhere else in the world. This was a product of people working together in the interests of the organisation. As a consequence, ECCO has become highly successful, embracing 31 Country Members and IBD specialists from 65 different nations and at its most recent congress in Barcelona, bringing together 4,282 specialists from 76 different countries. But size has its consequences and size necessitates structure.

**The danger is** that the application of science to organisational administration loses sight of humanity. A structure without humanity is like a skeleton without tissue: you need both to work to create a sentient being. So all the new structures in ECCO have a common purpose, of providing a framework through which we can all work to achieve the goal of improving care for patients. ECCO needs individual initiative. It needs new people to join committees.



Javier Pérez 'Aria da Capo', 2008  
(courtesy of Mario Mauroner Contemporary Art Vienna)

### **The personal challenge – from me to you – is:**

get involved with ECCO. At the very least – become a member ([www.ecco-ibd.eu](http://www.ecco-ibd.eu): it saves you EUR 300 to EUR 400 on registration for the 8th Congress of ECCO in Vienna in 2013 and brings you JCC, whose impact factor is soaring). Then, contribute to committees: so apply! All committees have places advertised this year. ECCO wants more people from Central and Eastern Europe, female representation, and new faces. Expertise is the deciding factor, like science, but demographics (like the humanities!) are taken into account. The decision-making process is defined on the website. The great

thing about ECCO is that it encourages change. Established experts who have contributed much to ECCO can move on or continue to represent ECCO through UEG(F), WGO and other organisations. But challenges work both ways. The challenge from you to me will be: tell me what is needed; I can't promise to deliver, but I can promise to consider attempting to do so.

**There is still a paradox:** although the essence of ECCO is the common good, deploring a personal profile, it is only the personal interaction with patients that will achieve ECCO's goal, because at the end of the day, it's patients who matter. If ECCO is to bridge that gap between structures, science and delivery, it needs commitment to ECCO from individuals. Reactions need catalysts. Improving care for patients needs a catalyst. That catalyst is you.



Simon Travis © ECCO Photographer

**SIMON TRAVIS**  
ECCO President

# Interview: President-Elect and Secretary

During the ECCO Congress in Barcelona, the General Assembly confirmed Séverine Vermeire as President-Elect and Silvio Danese as Secretary of ECCO

Both Séverine and Silvio are well-known faces, having been part of ECCO and engaged in the organisation for many years. When asked about her motivation to become ECCO President, Séverine told us: "I have been involved with ECCO since 2004 and have enjoyed every single minute of its growth and seeing it become so successful. I felt I wanted to contribute further and thought I had the energy, the will and the good intentions to make sure ECCO continues to be the place everybody wants to belong to or go to!" Likewise, Silvio felt that as ECCO Secretary he would have a chance to give something back to the organisation; he wishes to "actively contribute to its growth and expand its existing prominence as the prime international IBD organisation".

## Think global, stay local!

Looking ahead, the ambitious newly elected officers have set their sights high. Silvio says: "I believe that collaboration can be further enlarged on a global scale with greater involvement of colleagues from the United States and Asia through more proactive interactions with various ECCO initiatives. Though already in place, this mechanism should be boosted, and this will advance the field of IBD tremendously, particularly in terms of research activities." Séverine agrees, adding that "ECCO's projects and programmes are still insufficiently known in North America and Asia".

However, Séverine is also aware that ECCO's continuing growth and internationalisation poses some risks: "We need to make sure that we do not become the victims of our own success! We cannot grow eternally with this same format of one room, one programme. Quality remains the most important thing even if this means cutting down on, for instance, the size of the growing ECCO Congress." Most importantly, ECCO must not lose "the familial atmosphere", as Séverine puts it. She continues: "ECCO is a society that is very open to physicians, nurses, students and neighbouring specialties: the surgeons, the radiologists, the paediatricians. All are represented within our association and this close collaboration and exchange of opinions will, without a doubt, optimise care and research."

"ECCO should above all see where it can distinguish itself from other large societies, such as United European Gastroenterology and the American Gastroenterology Association, in order not to copy these, and to identify what concepts and structures can be utilised in a better way," Séverine remarks. "The structure of the congress is very different



Séverine Vermeire (ECCO President-Elect) and Silvio Danese (ECCO Secretary) © ECCO Photographer

from that of the larger meetings. There is plenty of space and opportunity for talented young people to interact and present their ideas and work, and there are also plenty of opportunities for cross-specialty interactions. The latter also happen at UEG Week or DDW meetings, but due to the size of the meetings, they are probably less successful."

## Objectives and orientations

The strengthening of the research activities of ECCO is a key objective for both the new President-Elect and the new Secretary. Silvio states, "ECCO has to do much more to improve research through securing considerably more funding. Stronger ties with patient organisations, private funding agencies and potential individual donors, and perhaps collaboration at the EU level, could help ECCO to effectively fundraise to support multinational initiatives."

Séverine agrees: "We should further focus on and promote collaborative research in Europe. One major aspect which will facilitate this is the creation of biobanks across Europe. ECCO has the knowledge and in house expertise to propose a core set of standards and materials so that we all have the same goals for our patients. By doing so, we shall put ourselves in a very strong position, not only in terms of funding agencies, but also in our collaboration with industry." And the need for a stronger partnership with the national and European patient organisations, with common goals, has certainly not been forgotten. "This becomes particularly relevant in terms of reciprocal needs with regards to research,

funding, patient and doctor education, spreading awareness of the disease, and creating tools for home care assistance, amongst other things," says Silvio. Séverine agrees: "There should be more awareness of the disease, with better care for the patients."

As President-Elect, Séverine hopes to be "as committed, approachable and driven as my predecessors. They all did it not for themselves, but for everybody who cares about IBD. Those who know me will know that I am very practical, efficient and quite straightforward; on the other hand, I am able to compromise, too, and I think this is important for a 'materfamilias' who wants to make sure the whole family is happy."

"I hope to maintain my enthusiasm in all the ECCO activities," Silvio says. "What was especially surprising and gratifying to me [when I first became part of ECCO] was that my young age was never an issue, but actually a plus, as one of ECCO's key beliefs is that young members are really the soul of the society – a remarkable and innovative way to attract young and enthusiastic minds and energy to this great clinical and scientific society. The active involvement of Y-ECCO is already a reality, but I am convinced that young members should be even more actively involved in all the scientific activities. After all, investing in Y-ECCO is truly investing in the tomorrow of ECCO."

**JOHAN BURISCH**  
Associate Editor ECCO News

**Séverine Vermeire, MD, PhD:**  
President-Elect of ECCO

**Born:** September 9, 1970  
**Civil status:** Married, one daughter  
**Current position:** Associate Professor of Medicine, University of Leuven, Belgium  
**Member of SciCom:** 2004-2009  
**Secretary of ECCO:** 2009-2011

Séverine graduated in medicine in 1995 from the Catholic University of Leuven, Belgium. Part of her training was done at the Universidad Nacional de Asuncion, Paraguay (1993) and at the Montreal General Hospital (McGill University), Montreal, Canada (2000-2001). In 2001, she obtained her PhD, entitled "Study on Genetic Polymorphisms and Serologic Markers in Inflammatory Bowel Disease", as a Fellow of the National Funds for Scientific Research of Belgium (FWO). Part of her PhD was done at the University of Oxford,

United Kingdom, at the Wellcome Trust Centre for Human Genetics with Professor Derek Jewell. Since 2003 she has been a full staff member at the Gastroenterology Department of the University Hospital Leuven and has been appointed Associate Professor at the Catholic University of Leuven, Belgium. Séverine joined the first Scientific Committee (SciCom) in 2004, where she spent five years until she was elected Secretary of ECCO in 2009.

Even as a child, Séverine wanted to become a doctor, but other possibilities were considered before making the final decision. "When I was 16-18 and started thinking of my future profession, I first wanted to do history and become an archaeologist, but then I also considered being a doctor or a lawyer!" Luckily she chose medicine and was inspired to become a gastroenterologist! "When looking back at this," Séverine recalls, "I enjoyed 'the abdomen' a lot from the moment I entered the

clinic as a student and also later, as a resident. It was Paul Rutgeerts who stimulated me early on, during my first year as a resident in internal medicine, to do gastroenterology and research, and Derek Jewell who further introduced me to the world of IBD genetics."

In between the clinic, the research and, of course, her duties as an ECCO Officer, Séverine still finds time to relax. "I enjoy my little daughter, Juliette, who is 3 now," Séverine tells us. "I cannot sit at home and do nothing when I am free, so we try to find fun things to do with our kid. I enjoy a good glass of red wine, breakfast outside in the garden, a nice restaurant in the evening, a good book – I am very into Latin-American writers. I would be lying to my many friends in IBD if I didn't mention that I also like "good shops" and nice clothes, shoes and bags. So I have to work hard!"

**Silvio Danese, MD, PhD:**  
Secretary of ECCO

**Born:** January 10, 1975  
**Civil status:** Married, two daughters and one son  
**Current position:** Head of the IBD Centre at the Istituto Clinico Humanitas, Milan, Italy  
**Member of SciCom:** 2007-2010  
(Y-ECCO representative)

Silvio graduated in medicine in 1999 from the Catholic University of Rome. He then started his Fellowship in Gastroenterology at the Policlinico Gemelli in Rome. From 2001 until 2004 he was a research associate in Dr. Claudio Fiocchi's laboratory, at the

Division of Gastroenterology at Case Western Reserve University, Cleveland, Ohio, United States. In 2005 he became a specialist in gastroenterology, and in 2006 he obtained a PhD in physiopathology. Silvio Danese's main areas of research interest are the investigation of the fundamental mechanisms underlying IBD pathogenesis and new imaging modalities in IBD, and he is involved in several clinical trials.

Silvio joined ECCO in 2007 and was elected a member of SciCom the same year, on which he sat for three years. Similar to Séverine, he had considered other options before choosing gastroenterology. "I wanted to be a poet and study literature. But I always wanted to be a doctor as well, so poetry and literature

have remained a pursuit for my free time." Silvio chose gastroenterology purely because of his love for research: "In my medical school, when I was a student, I was always fascinated by research, and Professor Gasbarrini was a very active researcher. After that, Claudio Fiocchi was the person who most influenced my career."

Off duty, family is a great part of Silvio's life. "I am extremely busy at home, as I have twin girls aged two and a boy who is eight months old. So I try to spend all the time I have with them and my wife. As soon as I have three days free, we go to our "buen retiro" in Tuscany, our country house among the vineyards!"

## ECCO Elections

Dear ECCO Friends,  
notice is hereby given that the following positions are open for election:

- Scientific Officer (Governing Board)
- Education Officer (Governing Board)
- ClinCom Members (Clinical Research Committee)
- SciCom Members (Scientific Committee)
- EpiCom Members (Epidemiological Committee)
- S-ECCO Members (Surgeons of ECCO)
- P-ECCO Members (Paediatricians of ECCO)

- Y-ECCO Members (Young ECCO)
- EduCom Member (Education Committee)
- GuiCom Members (Guidelines Committee)
- N-ECCO Members (Nurses of ECCO)

**Deadline for receipt of nominations is September 21, 2012.**

For detailed information about the open positions please visit the ECCO website at [www.ecco-ibd.eu](http://www.ecco-ibd.eu).

With best regards,  
ECCO Governing Board



European  
Crohn's and Colitis  
Organisation

# e-Learning



## Upcoming in 2012 and exclusive for ECCO Members:

- advanced e-learning opportunities in Inflammatory Bowel Disease throughout Europe
- secure, high level, up to date and interactive education with easy and equal access

## With core features such as

- interactive case-based courses with consecutive levels and cross reference to modules
- multimedia reference material in a searchable e-Library
- integrated pre, interim and post tests linked to CME accreditation

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

## Call for applications for ECCO Fellowships, Grants and Travel Awards 2013

**Deadline for applications for ECCO Fellowships, Grants and Travel Awards: October 1, 2012**

ECCO has established Fellowships, Grants and Travel Awards to encourage young physicians in their career and to promote innovative scientific research in IBD in Europe.

**Fellowships** have been created for individuals younger than 40 years who submit an original research project which they wish to undertake abroad in a European hosting laboratory and/or department that has agreed to host and guide the Fellow for the duration of the Fellowship (one year) and that is responsible, together with the Fellow, for the successful completion of the project. Fellowships are awarded a total of EUR 40,000 and are given during the annual ECCO Congress.

Grants are created to support good and **innovative** scientific, translational or

clinical research in Europe. The guidelines for ECCO Grants are very similar to those for the Fellowships, with the exception that the research is typically undertaken in the institution of the applicant. ECCO Grants are awarded EUR 20,000 each and will also be given during the annual ECCO Congress.

The **Travel Awards** were established in 2007 as an opportunity for young investigators to visit different IBD centres in Europe, to learn scientific techniques or to be a clinical observer. Incentives are available for applicants from Central and Eastern Europe.

**NEW:** For the first time IBD nurse members of ECCO can apply for the **N-ECCO Travel Award**, which provides nurses with the opportunity to visit another European centre to observe

nursing care, in recognition of the fact that observational learning is essential in enabling nurses to develop within a role.

For detailed information on Fellowships and Grants, including eligibility and the submission process, please visit the ECCO website [www.ecco-ibd.eu/index.php/what-we-do/fellowships-and-grants](http://www.ecco-ibd.eu/index.php/what-we-do/fellowships-and-grants).

We look forward to your application!

Kind regards,

**ANDREAS STURM**  
SciCom Chair

## Call for a new topic for Scientific Workshop 4

**Deadline for response: September 15, 2012**

SciCom is launching a fourth scientific workshop, and a new topic needs to be identified. If you are interested, please send a proposal for a new topic, including a title and a 100-word supporting statement, to the ECCO Office ([ecco@ecco-ibd.eu](mailto:ecco@ecco-ibd.eu)) before September 15, 2012. SciCom will shortlist three topics, which will be discussed at the workshop meeting during UEGW 2012. One topic will be selected. The organisation of the workshop will follow the same principles as previously:

1. Call for topics: June 20, 2012; deadline for response: September 15, 2012
2. Decision on the topic by SciCom by October 1, 2012, followed by selection of a steering committee (three members: one young clinician scientist and one more experienced KOL plus one member

representing the SciCom).

3. Meeting of the SciCom and the steering committee at UEGW 2012: definition of key areas of interest and focus of the scientific workshop.
4. Open call to participate after UEGW.
5. Decision on participants and group leaders by end of November 2012 by the SciCom and the steering committee. Distribution of allocated questions to the participants by the group leaders.
6. Meetings organised within groups, at the discretion of the group leaders and depending on the progress and needs of the group, including possibly at DDW 2013.
7. Meeting at ECCO 2013: discussion within groups on the results of literature reviews and synthetic plenary presentation. Planning of the manuscripts.

8. Meeting at UEGW 2013 in the individual working groups, discussing the outcome and manuscripts.
9. End of January 2014: deadline for submission of the last scientific workshop manuscript. The submission should be made between June 2013 and January 2014.
10. Meeting at ECCO 2014: plenary presentation and working session to select research project.

Kind regards,

**EDOUARD LOUIS**  
SciCom Member

# Special article: 7th Congress of ECCO in numbers

Another record attendance at the 7th Congress of ECCO in Barcelona

The 7th Congress of ECCO – Inflammatory Bowel Diseases 2012, which took place on February 16-18, 2012 in Barcelona, Spain, attracted another record number of 4,282 delegates from 76 different countries. Since the inaugural ECCO Congress in 2006 in Amsterdam, at which there were 350 delegates, participant numbers have steadily increased, as shown in the graph below:

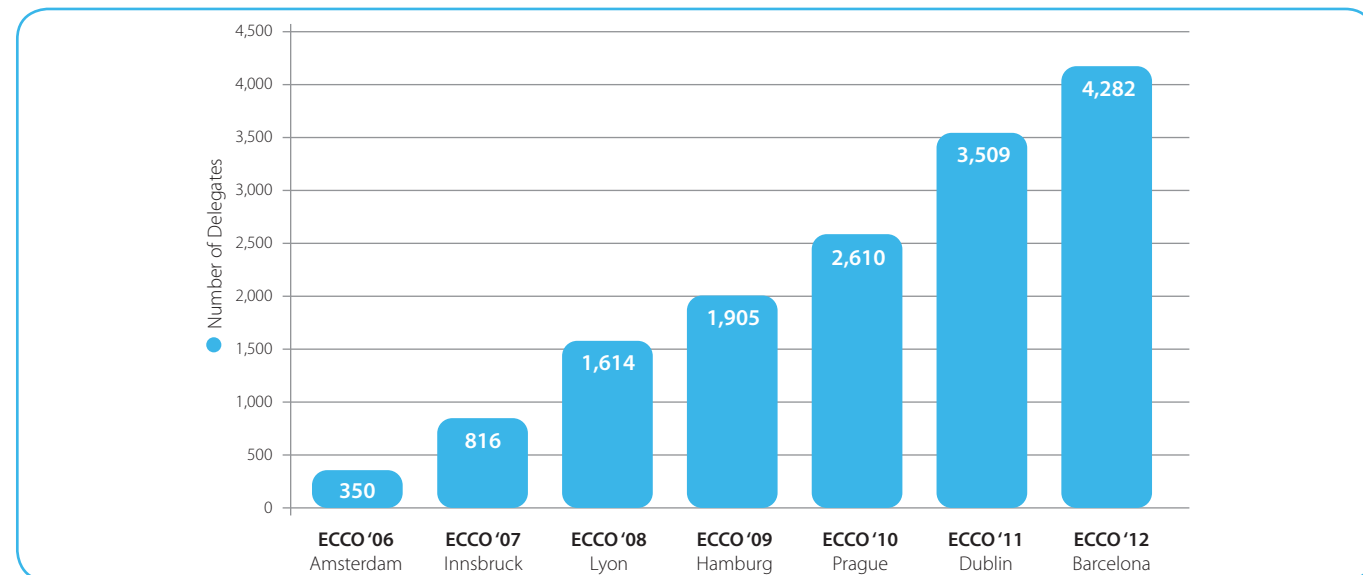


Figure 1: ECCO Congress participation 2006-2012 © ECCO Office

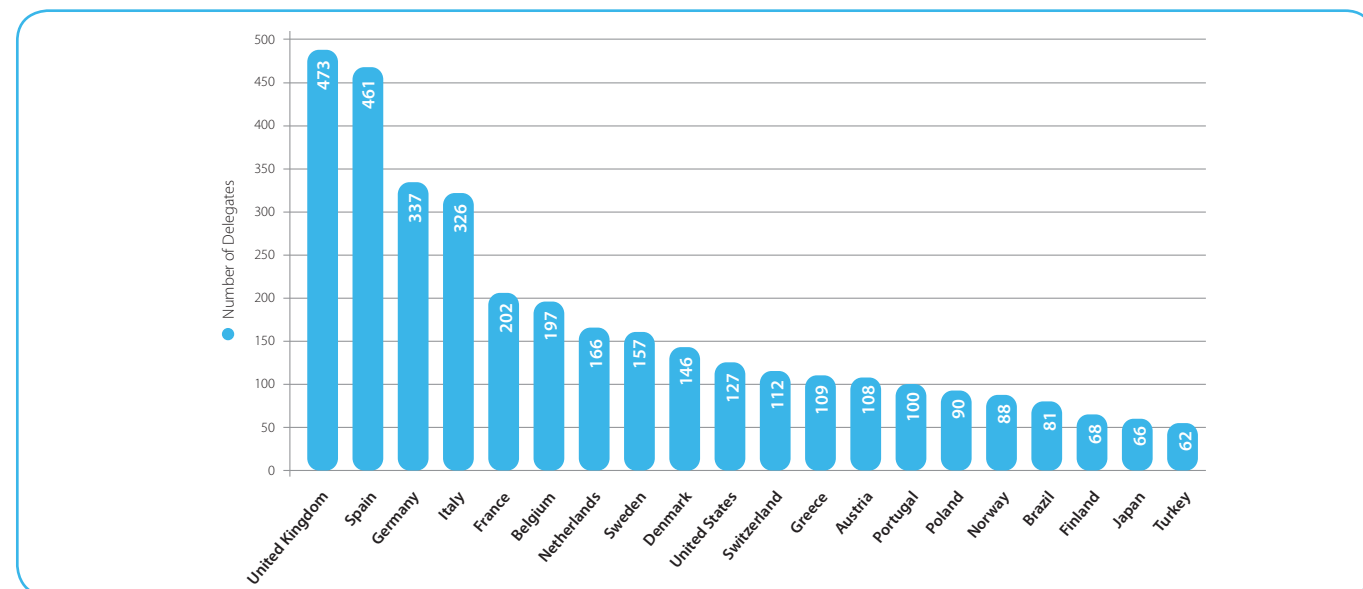


Figure 2: ECCO Congress participation 2012 - Top 20 countries © ECCO Office

The following pie chart represents the attendance at the 7th Congress of ECCO in total numbers from a continental perspective. Approximately 85% of all participants came from Europe and about 15% from outside of Europe.

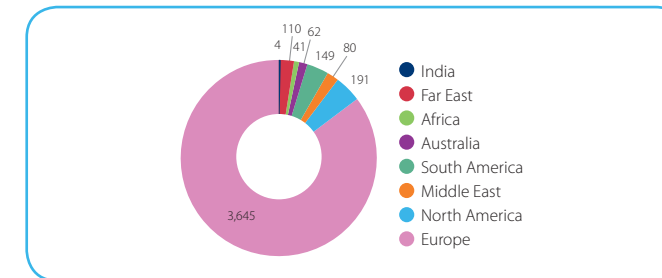


Figure 3: ECCO Congress participation 2012 – Continental perspective © ECCO Office

The graph below illustrates the professions represented at the 7th Congress of ECCO. The majority of participants were physicians (47%), followed by industry (13%) and scientists (12%).

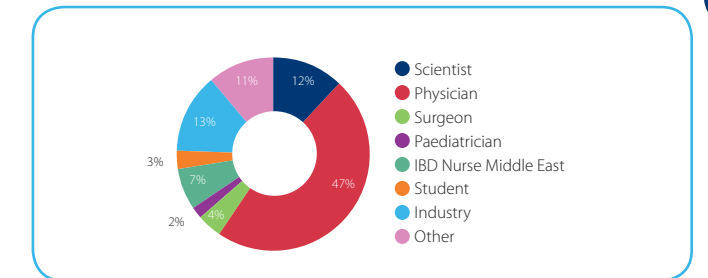


Figure 4: ECCO Congress participation 2012 – Professions © ECCO Office

### High quality abstracts

A key component of the success of the ECCO Congress is the rising number of high-quality abstracts accepted for both oral and poster presentation. An outline of the evolution of abstract submission is displayed here:

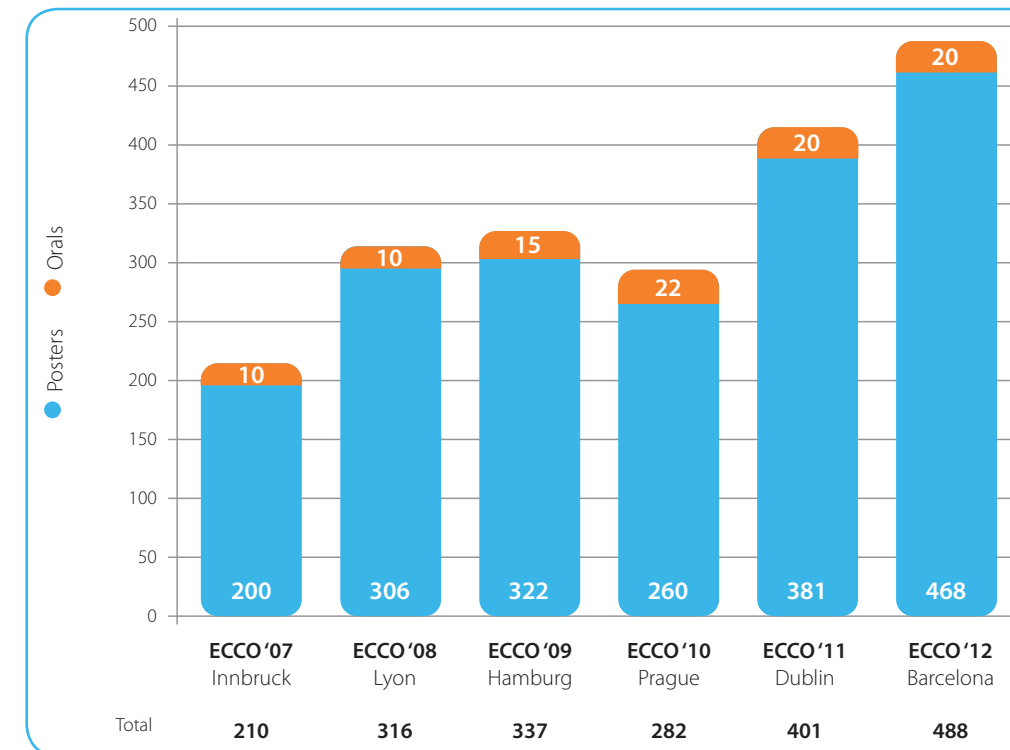


Figure 5: Accepted oral and accepted poster presentations 2007 – 2012 © ECCO Office

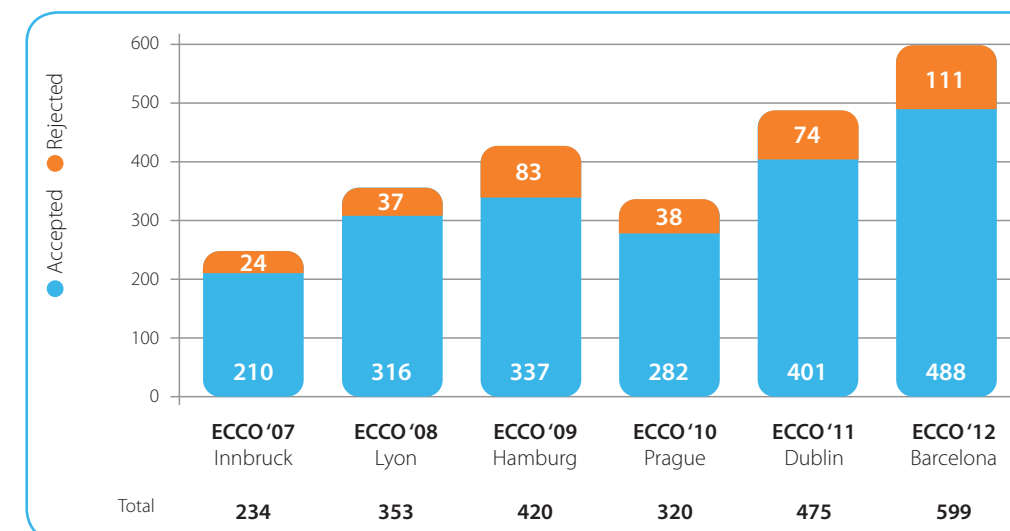


Figure 6: Accepted versus rejected abstracts 2007 – 2012 © ECCO Office

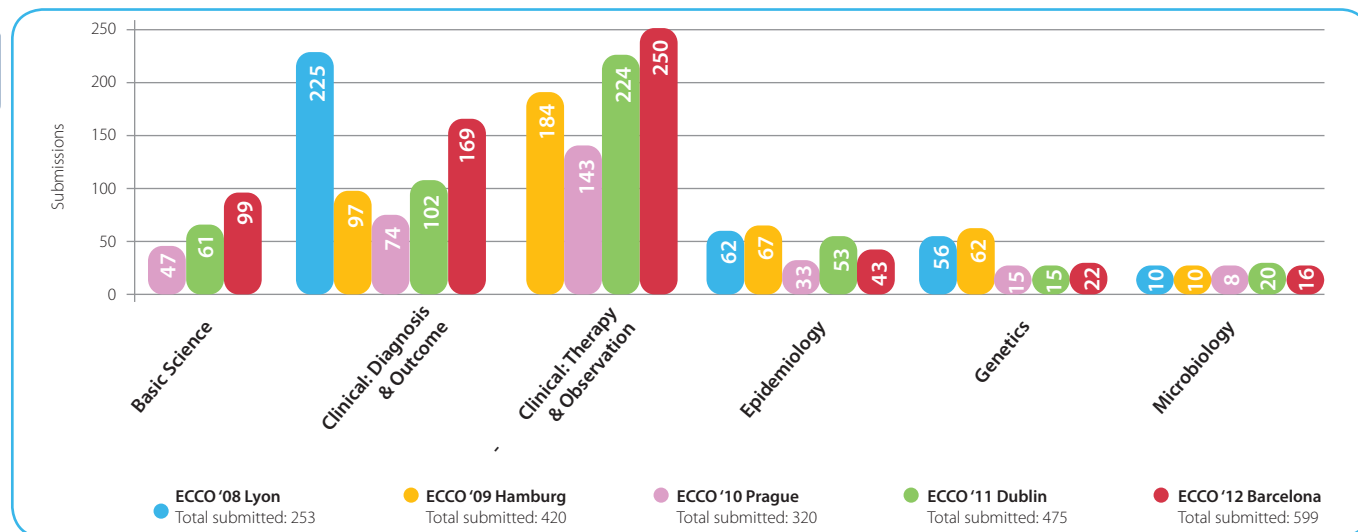


Figure 7: Abstracts 2012 – category split © ECCO Office

**Industry Exhibition**

This year's industry exhibition attracted **20 exhibitors**, mainly from the pharmaceutical but also from the endoscopic, device/instrumentation, medical, publishing and non-profit sectors. The **total net exhibition area was 816 m<sup>2</sup>** – another record in the history of ECCO Congresses.

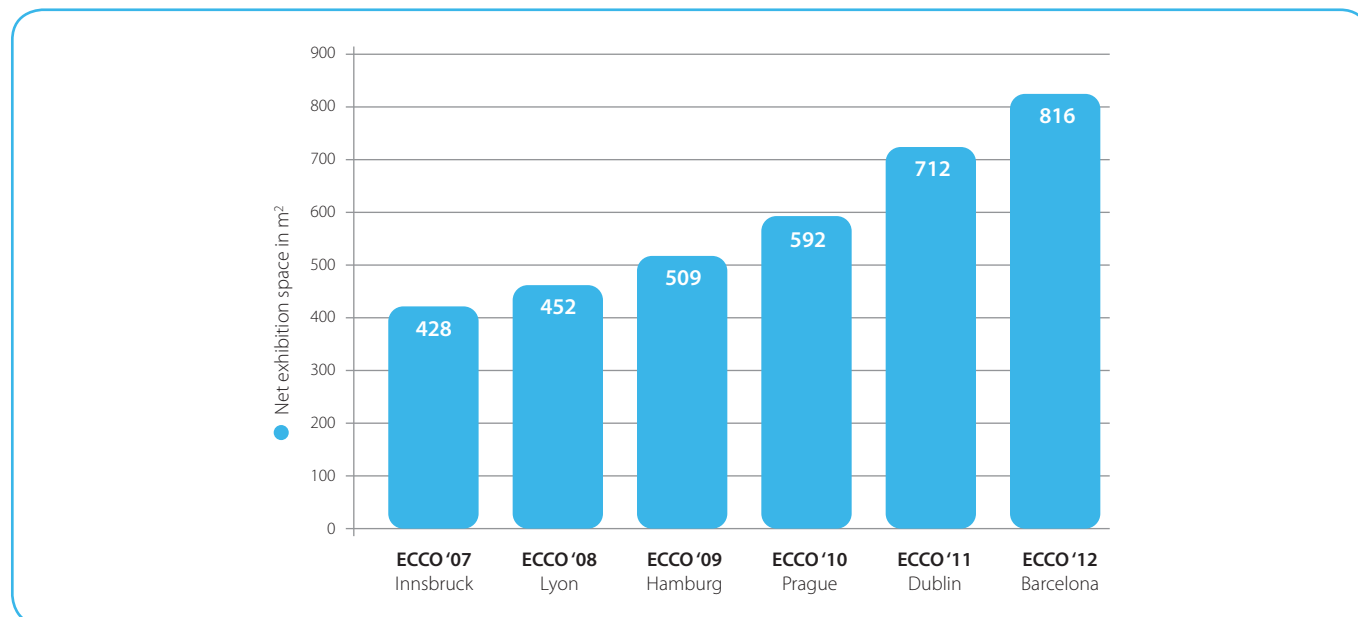


Figure 8: Net exhibition space 2012 in m<sup>2</sup> © ECCO Office

**More statistics...**

Detailed statistics and impressions of the 7th Congress of ECCO can be viewed online at [www.ecco-ibd.eu](http://www.ecco-ibd.eu). Furthermore, video recordings of scientific talks are available for ECCO Members in the closed members' area at [www.ecco-ibd.eu](http://www.ecco-ibd.eu) (availability of recordings subject to speaker authorisation).

**Best posters at the 7th Congress of ECCO**

ECCO congratulates the winners of the best posters at the 7th Congress of ECCO

- Zuzana Zelinkova** (P275 – Evaluation of the discontinuation of infliximab during pregnancy in inflammatory bowel disease patients)
- Borut Klopčič** (P029 – Oral iron supplementation promotes inflammation and colorectal carcinogenesis in a mouse model of colitis-associated cancer)
- Andrea Cassinotti** (P362 – Autologous haematopoietic stem cell transplantation without CD34+ cell selection for refractory Crohn's disease: The Milan experience after 5 years)



Best posters of the 7th Congress of ECCO 2012 © ECCO Photographer

# 1st EpiCom Workshop at the 7th Congress of ECCO

During the ECCO Congress in Barcelona in February 2012, the 1st Epidemiological Committee (EpiCom) Workshop was held, chaired by Peter Lakatos (EpiCom Chair) and Pia Munkholm (former chair of EpiCom).

The aim of the workshop was to introduce the basic methodology of epidemiological studies to the participants, using studies from all over the world to illustrate the importance of design and the difficulties encountered in such studies. With 65 persons signing up for the event, the workshop quickly reached its maximum capacity, making it a successful premier.



Pia Munkholm at the 1st EpiCom Workshop © ECCO Photographer

Tine Jess initiated the meeting with a presentation on the evolution of epidemiology in IBD and not least the methodological pitfalls and key points in the conduct of epidemiological studies. Dr. Jess discussed the rising incidence and prevalence of IBD over time, which may to some extent be explained by greater awareness of IBD, better diagnostic tools and easier recording of patients. Well-conducted incidence studies are essential for the conduct of prognostic studies, which need to represent the broad and unselected spectrum of patients with IBD. This fact was recognised almost half a century ago by Truelove and colleagues, who paved the way for today's methodologically well-conducted prognostic studies.



Tine Jess during her talk on the evolution of epidemiology in IBD © ECCO Photographer

Ebbe Langholz continued the description of incidence and prognostic studies in IBD with a particular focus on the Scandinavian experience. In Scandinavia, detailed registration of citizens and free access to healthcare provide a unique tool for inclusion and follow-up of IBD patients in unselected cohort studies. However, researchers still need to choose between the conduct of regional cohort studies, with manually collected detailed information on patients but limited power to study rare outcomes, and national cohort studies, with less detail on IBD but better potential for studying rare outcomes.

Laurent Peyrin-Biroulet provided an interesting comparison of differences in the incidence and prevalence of IBD in the United States and France. In particular, the ratio between CD and UC is much higher in France than in the United States. This difference remains unexplained but it may be due to a higher prevalence of smokers in France or to differences in nutrition and, potentially, vitamin D status between the populations. Another explanation may be differences in the completeness of registration of IBD cases, which may depend on the number of patients seen in private practices rather than in hospital settings.



Audience at the 1st EpiCom Workshop © ECCO Photographer

Epameinondas Tsianos described the impressive first cross-European initiative within IBD epidemiology – the EC-IBD study of patients collected across Europe in 1991-1993, which now provides 15-year follow-up data. In line with a recent meta-analysis on colorectal cancer in UC patients, only 1.3% of EC-IBD patients developed colorectal neoplasia during the first 15 years in the EC-IBD study. The North-South gradient in incidence of IBD observed in the EC-IBD study may be paralleled or followed by an East-West gradient. This is currently being investigated in the ongoing EpiCom cohort study across Europe, which is revealing a high

incidence in countries as different as the Faroe Islands and Hungary.

Peter Lakatos described the thorough recording of IBD patients in Hungary, where patients have free access to health care and a personal registration number, similar to conditions seen in Scandinavia. Further, contact with GPs assures complete registration of IBD cases and biannual IBD visits in hospitals assure complete follow-up data. Diagnostic tools have not changed over time in Hungary and still the incidence has risen – both in children and adults – to levels around those seen in the United States. Further, the prevalence of inflammatory behaviour is declining in Hungary.

Following the individual talks, the workshop participants worked in five groups on future perspectives of the ongoing cross-European EpiCom incidence study, followed by a presentation of ideas in a plenary session chaired by Johan Burisch and Matteo Martinato. There were many suggestions for spin-off projects on this cohort, including proposals to study:

1. First year phenotype, disease activity, hospitalisation rates, and medical and surgical treatment, including observed adverse events,
2. Predictors of the course of disease, such as age, environmental factors including NSAIDs and vaccinations, and non-invasive biomarkers,
3. Adherence to medical treatment,
4. Prevalence of coeliac disease,
5. Rate of iron deficiency anaemia and vitamin D deficiency in newly diagnosed patients,
6. Rates of osteopenia and osteoporosis and
7. Prevalence of other autoimmune diseases.

In an inspiring and dedicated atmosphere, the 1st EpiCom Workshop clearly demonstrated that epidemiological research within ECCO is conducted according to the highest standards. A fruitful combination of key speakers with expertise in the field and committed participants led to interesting discussions and ideas for future research. In line with this, the group work demonstrated the great value of the new EpiCom cohort and the many potential future studies that it may bring.

On behalf of EpiCom,

**JOHAN BURISCH, TINE JESS**  
EpiCom Members

# Introducing the new members and the “road map” of EduCom



Sandro Ardizzone © ECCO Photographer



James Lindsay © ECCO Photographer



Stephan Vavricka (Source: Stephan Vavricka)

Having served as a member and chair of the EduCom for six consecutive years, **Gert van Assche** (Belgium) is now leaving the committee. Gert's contribution to EduCom has been enormous in many different ways: his scientific excellence and leading position amongst world leading experts in the field of IBD, his solid and sober character and his great sense of humour along with his efficiency, practicality, infectious enthusiasm and visionary ideas have ensured a period of “charismatic leadership” and joyful collaborative work for us all. Gert will continue as a member of a new innovative initiative, the e-Learning task force, which is expected to further boost the educational activities of ECCO, covering all scientific and clinical aspects of IBD.

The new chair, **Gerassimos Mantzaris** (Greece), is delighted to take over Gert's duties for the next two years but he also already feels the huge burden to prove himself a worthy successor.

The EduCom welcomes three new members, James Lindsay (United Kingdom), Sandro Ardizzone (Italy) and Stephan Vavricka (Switzerland), who will work together with Charlie Lees (United Kingdom). Janneke van der Woude (The Netherlands) will continue to lead the educational activities of ECCO as Education Officer and co-Chair of the Operational Board of ECCO.

#### A short introduction to our new members:

**James Lindsay** is the leading clinician for the large adolescent and adult IBD services in Bart's and the London NHS Trust. He has effectively chaired working groups on updates to the consensus guidelines for Ulcerative Colitis and Crohn's Disease and serves as the National Representative of the United Kingdom to ECCO. He has considerable experience in organising and delivering IBD educational activities for

physicians, nurses and patients both in the United Kingdom and worldwide. James will mainly be involved in the organisation of the IBD Intensive Advanced Course for Junior Gastroenterologists and we are confident that he will further boost its quality and content.

**Sandro Ardizzone** is Head of the IBD Clinic at the Luigi Sacco University Hospital in Milan, Italy. He is a very competent endoscopist and highly respected IBD expert. He has huge experience in pioneering department-, team- and industry-initiated clinical trials, and is a world leading expert in haematopoietic stem cell auto-transplantation. He has considerable experience in educational and learning techniques and has participated in the development of ECCO-OMED Endoscopy Guidelines and the 2<sup>nd</sup> ECCO Pathogenesis Workshop. Sandro is expected to handle the logistics of the ECCO Educational Workshops. This is a new challenge ante portas after the decision of the Governing Board that as of 2012, only ECCO Members can attend workshops.

**Stephan Vavricka** is a rising IBD star. He is Chief in the Department of Gastroenterology at Triemli Hospital in Zurich and has extensive experience in developing educational materials. Stephan was the President of IBDnet gastroenterologists, which established the Swiss IBD cohort study, and has been the organiser of many different national IBD teaching courses for trainees, residents, private care gastroenterologists and nurses. Stephan is expected to offer fruitful ideas and brainstorming for the development of new cases and educational formats, and will liaise with the Guidelines Committee on several interdisciplinary projects.

#### The “road map” of EduCom:

The new EduCom is confronted by both old and new tasks. Although last year the work

of the EduCom became more focussed on educational activities after the formation of a separate Guidelines Committee, the goals remain the same: “to strengthen the evidence-based knowledge about IBD both in ECCO Member Countries and beyond and develop and implement a panel of educational formats intended for the different stakeholders and interest groups within ECCO”. Since the early days, the Education Committee has been doing this by organising the IBD Intensive Advanced Course and by providing educational case-based workshops.

The **Intensive Advanced Course designed for Junior Gastroenterologists** with a special interest for IBD is very well attended. A full report on this year's course was recently published in the first issue of ECCO News in 2012. Charlie Lees, course director in the last two years, has further improved its content with a continuous update of topics, the introduction of tandem talks and new educational tools, a new syllabus format and content, and real-time evaluation of the speakers and the trainees. The EduCom regrets having to turn down many applicants for this advanced course, but we feel that a small group is necessary to ensure an interactive and safe learning environment. Although there are many applicants, not all countries are equally represented. Therefore, *the Education Committee would again like to encourage all National Representatives to inform and motivate young physicians in their countries to apply for this excellent opportunity to be educated by key opinion leaders in the field of IBD.*

**ECCO Educational Workshops**, another important educational asset of the EduCom, aim at harmonising the practice of IBD in member countries via interactive cases that epitomise the ECCO Guidelines on the diagnosis and management of IBD and state

of the art lectures. The slide desk of cases is being continuously updated and enriched with new educational material to catch up with the feverish activity in ECCO to incorporate the accumulated evidence into new and updated IBD guidelines. Gerassimos Mantzaris has led this activity in the past three years and we hope that Sandro and Stephan, with their exceptional skills, will manage the workshops in the best possible way in future years.

This year we have scheduled *three European workshops, in Athens (Greece), Sibiu (Romania) and Bratislava (Slovakia)*. We hope the last-

mentioned will be a joint event for Slovakian, Czech and Hungarian members of ECCO. Registration for the Greek workshop is already open for members on the ECCO website. Invitations for ECCO Country Members that are eager to *host an ECCO Educational Workshop in 2013* will be released soon.

In addition, the Education Committee provides educational material to workshops in overseas countries that seek close educational co-operation and any other sort of affiliation with ECCO. *This year, two overseas workshops will take place in South Africa and Japan.*

We anticipate that the coming years will witness a booming educational ECCO along with the **implementation of e-Learning** as an excellent tool enabling all country members to remain up to date in IBD.

On behalf of the Education Committee,

**JANNEKE VAN DER WOUDE**  
Education Officer

**GERASSIMOS J. MANTZARIS**  
EduCom Chair

## Call for Nominations of Participants at the 11<sup>th</sup> IBD Intensive Advanced Course

The **11<sup>th</sup> ECCO Intensive Advanced Course in IBD** for residents, fellows in gastroenterology and junior faculty will take place in **Vienna, Austria** from **February 13–14, 2013**, just prior to our next congress. We are pleased to inform you that the preliminary programme of this course is already available (see Table 1).

ECCO wants to make this course as attractive as possible for participants. We are therefore limiting the general number of participants from each ECCO Country Member to 2 in order to provide for a more interactive atmosphere. Three seats will be open for countries with a population of over 50 million people (this includes: Italy, France, Germany, Russia, United Kingdom and Turkey).

#### Minimum criteria for nominees:

1. ECCO Member status (2013)
2. Trainees at least in their third year with preferably one year of GI experience
3. Should demonstrate a sufficient level of English to follow the course

#### Nomination process for candidates from ECCO Country Members:

**Candidates who are interested should contact their National Representatives** (see page 34) well in advance.

Participants are selected in their country, by a national system left to the responsibility of the National Representatives of each ECCO Member Country.

The National Representatives submit their nominations with a **CV** (containing full contact details, position and information about hospital affiliation) and a **letter of**

**intent** for each candidate:

**Deadline for receipt of nominations** from ECCO National Representatives: **September 7, 2012**

Nominated candidates will be informed about the status of their application by the beginning of October 2012.

#### Nomination process for candidates from outside of Europe:

In line with the highly appreciated cooperation with ECCO's global friends, a certain number of course places will be reserved for candidates from outside of Europe.

Candidates who are interested should contact the ECCO Office ([j.gabriel@ecco-ibd.eu](mailto:j.gabriel@ecco-ibd.eu)) well in advance.

**CHARLIE LEES, JAMES LINDSAY**  
Course Directors

**Table 1: Preliminary Programme of the 11<sup>th</sup> IBD Intensive Advanced Course (as of May 2012)**

Wednesday, February 13, 2013		Thursday, February 14, 2013	
07:30 – 08:00	Arrival and distribution of voting pads	07:30 – 08:00	Arrival and distribution of voting pads
08:00 – 08:15	Welcome	08:00 – 10:20	<b>V. Interactive case discussion and lecture session</b> Lead discussant: Charlie Lees
08:15 – 08:45	Pre-course test	08:00 – 09:00	<b>Tandem talk:</b> Fistulising and stenosing disease: medical and surgical approaches
08:45 – 10:45	<b>Session I. Lecture session</b>	09:00 – 10:00	<b>Case-based discussion:</b> The patient with severe inflammatory Crohn's disease
08:45 – 09:15	<b>IBD: Epidemiology and environmental factors</b>	10:00 – 10:20	<b>Discussion</b>
09:15 – 09:45	<b>The genetics of IBD</b>	10:20 – 10:45	Coffee break
09:45 – 10:45	<b>Tandem talk:</b> IBD therapeutic targets and drugs: New and old	10:45 – 12:15	<b>VI. Session: Drug therapy session</b>
10:45 – 11:15	Coffee break	10:45 – 11:15	<b>Endoscopy for inflammatory bowel disease</b>
11:15 – 12:40	<b>II. Seminar session</b>	11:15 – 11:45	<b>Monitoring drug therapy with biomarkers, drug levels and antibody testing</b>
11:15 – 11:55	<b>Seminar I: IBD and pregnancy</b>	11:45 – 12:15	<b>Vaccinations, immunisations and opportunistic infections in IBD - A case-based guide</b>
	<b>Seminar II: Paediatric IBD</b>	12:15 – 12:30	<b>Feedback and closing remarks</b>
12:00 – 12:40	<b>Seminar I: IBD and pregnancy</b>		
	<b>Seminar II: Paediatric IBD</b>		
12:40 – 13:15	Lunch break		
13:15 – 15:30	<b>III. Interactive case discussion and lecture session</b>		
13:15 – 14:00	<b>Case-based discussion:</b> The patient with watery diarrhoea, abdominal pain and weight loss		
14:00 – 14:30	<b>Cancer surveillance and chemoprevention in colitis</b>		
14:30 – 15:30	<b>Tandem talk:</b> Acute severe ulcerative colitis: Management including medical and surgical rescue therapy		
15:30 – 16:00	Coffee break		
16:00 – 18:00	<b>IV. 6<sup>th</sup> Y-ECCO Workshop</b>		



# ECCO Educational Workshops 2012

-  **24<sup>th</sup> ECCO Educational Workshop**  
Tokyo, **Japan** – June 17, 2012
-  **25<sup>th</sup> ECCO Educational Workshop**  
Athens, **Greece** – July 7, 2012
-  **26<sup>th</sup> ECCO Educational Workshop**  
Durban, **South Africa** – August 10, 2012
-  **27<sup>th</sup> ECCO Educational Workshop**  
Sibiu, **Romania** – September 20, 2012
-  **28<sup>th</sup> ECCO Educational Workshop**  
Bratislava, **Slovakia** – November 16, 2012



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## How to perform an ECCO Survey – a new standard operating procedure

The ECCO Office and various ECCO Committees are frequently asked to assist with surveys or questionnaires to be distributed to ECCO Members in order to obtain further information or answers in relation to specific topics and questions of relevance to IBD.

These surveys consume significant resources at the ECCO Office and also have the potential to irritate ECCO Members if conducted in an unregulated manner. A standard operating procedure (SOP) has been created for ECCO-endorsed and ECCO-managed surveys. Key points of this SOP are summarised below, but the complete SOP can be downloaded from ECCO's homepage ([www.ecco-ibd.eu](http://www.ecco-ibd.eu)).

*The following information should be included in a proposal:*

### Background

- An explanation of why the survey is relevant to IBD
- Relevant existing information, especially data from pilot trials
- Identification of who is to be surveyed (ECCO Members, other societies, etc.)

### Aim(s)

- Description of the question(s) to be addressed by the survey
- Identification of the primary and secondary hypotheses

### Methodology

- An outline of the survey
- Statistical estimates of the numbers who must respond to enable valid conclusions to be drawn and to answer the primary hypothesis
- Description of measures for following up non-responders
- Explanation of what statistical analyses will be performed and who will be in charge of these analyses
- The proposed timeframe of the project, including the proposed start date of the survey, expected database lock, statistical analysis and expected date of data presentation

### Budget and ROI

- Detailed list showing the anticipated costs of the survey
- The funding source
- Identification of who owns the data and the intellectual property (especially important if the survey extends beyond ECCO Members)
- The implications for the ECCO Office: clarification of their role

### Other matters

- Further relevant information, e.g. whether other societies will participate or relationship with regard to industry
- Intended use of the data
- Publication: statement as to how ECCO will be acknowledged, assuming ECCO endorses the survey

Requests for a survey should be submitted to the ECCO Office ([ecco@ecco-ibd.eu](mailto:ecco@ecco-ibd.eu)). Requests will be distributed to responsible Committee Chairs and ECCO Officers (SciCom, GuiCom, ClinCom, EpiCom, Scientific Officer and Education Officer). Based on their recommendation, ECCO's Governing Board will decide whether the survey will be endorsed by ECCO.

**AXEL DIGNASS**  
GuiCom Chair

**ANDREAS STURM**  
SciCom Chair

## ECCO Guidelines: Current Overview

Table 1: Guideline Programme

New	Call	Publication	Updates	Call	Publication
Paediatric UC	2011	2012	Ulcerative Colitis	2010	2012
Imaging	2011	2012	Opportunistic Infections	2012	2012-2013
Histopathology	2011	2012	Anaemia	2012	2013
Endoscopy	2012	2013	Crohn's Disease	2012	2014
Nursing	2012	2013	Pregnancy	2013	2014
Surgical UC	2012	2013-14	<b>To be setted</b>		
Paediatric CD	2012	2013	Nutrition	Tba	Tba
			Malignancies	Tba	Tba



## Call for Nominations of Participants at the 4<sup>th</sup> N-ECCO School in Vienna

At the 8<sup>th</sup> Congress of ECCO in Vienna, the N-ECCO Committee will host the educational activity for IBD nurses, **N-ECCO School**, for the fourth time. ECCO intends to give young nurses, who might still be in training and have an interest in IBD, the possibility to attend an IBD-focussed course. The aim of this programme ultimately is to improve nurse education throughout Europe.

The 4<sup>th</sup> N-ECCO School will take place on **Thursday, February 14, 2013.**

The call for nomination of participants is being sent out to all N-ECCO National Representatives in June 2012.

Interested candidates are encouraged to **apply for nomination via the N-ECCO National Representative of their country** (see page 34). Places are limited to one nurse per country!

Some financial support from EFCCA (European Federation of Crohn's and Ulcerative Colitis Associations) is available

to cover nurses' costs incurred in attending the School. For further information, please visit [www.ecco-ibd.eu](http://www.ecco-ibd.eu).

**Deadline for nominations:  
September 3, 2012**

**PATRICIA DETRE**  
N-ECCO Committee Member

**Table 1: Preliminary programme of the 4<sup>th</sup> N-ECCO School (as of May 2012)**

### Thursday, February 14, 2013

07:45–08:45	Breakfast satellite symposium
09:00–09:05	General introduction and opening remarks
09:05–09:15	Welcome and introduction
09:15–12:30	Session 1: Diagnosis and assessment
09:15–09:45	English terminology for IBD nurses
09:45–10:15	Anatomy and physiology of the GI tract – Pathophysiology of IBD
10:15–11:00	Diagnosing IBD and assessing disease activity
11:00–11:30	Coffee break
11:30–12:00	Overview of medical treatment
12:00–12:30	Surgery in IBD
12:30–15:15	Session 2: Case studies - Disease management
12:30–13:15	Workshop 1 – UC management (Group A) Workshop 1 – CD management (Group B)
13:15–14:30	Lunch break
14:30–15:15	Workshop 2 – UC management (Group B) Workshop 2 – CD management (Group A)
15:15–16:30	Session 3: General management in IBD
15:15–16:00	Nutritional aspects in IBD - Children with IBD
16:00–16:30	Nursing roles in IBD management
16:30–16:45	Closing remarks
17:00–18:00	Afternoon satellite symposium
18:15–20:00	N-ECCO National Representatives meeting (N-ECCO Representatives only)



Audience at the 3<sup>rd</sup> N-ECCO School 2012, Barcelona  
© ECCO Photographer



Audience at the 3<sup>rd</sup> N-ECCO School 2012, Barcelona  
© ECCO Photographer



Audience at the 3<sup>rd</sup> N-ECCO School 2012, Barcelona  
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Participants of the 3<sup>rd</sup> N-ECCO School © ECCO Photographer

## S-ECCO: Current activities

### S-ECCO: Mission

- Promote cooperation between surgeons and gastroenterologists in IBD research
- Foster education and patient care
- Coordinate European surgical research, guidelines and registry in IBD
- Provide surgical expertise and input for all ECCO activities

### S-ECCO: Current activities

- Development of guidelines (Current project: ECCO Consensus on Surgery in Ulcerative Colitis)
- Organisation of the 2<sup>nd</sup> S-ECCO IBD Masterclass at the 8<sup>th</sup> Congress of ECCO, Vienna, Austria, February 2013
- Coordination of research studies
- Position statements and surgical papers



Audience at the 1<sup>st</sup> S-ECCO Masterclass  
© ECCO Photographer

## Significantly increased pregnancy rates after laparoscopic restorative proctocolectomy: a cross-sectional study

Bartels SA<sup>1</sup>, D'Hoore A<sup>2</sup>, Cuesta MA<sup>3</sup>, Bendsdorp AJ<sup>4</sup>, Lucas C<sup>5</sup>, Bemelman WA<sup>1</sup>. Significantly increased pregnancy rates after laparoscopic restorative proctocolectomy: a cross sectional study. *Ann Surg.* 2012 [Epub ahead of print]

- 1 Department of Surgery, Academic Medical Center, Amsterdam, the Netherlands,
- 2 Department of Abdominal Surgery, University Hospital Gasthuisberg Leuven, Belgium,
- 3 Department of Surgery, VU University Medical Center, Amsterdam, the Netherlands,
- 4 Department of Obstetrics and Gynaecology, Academic Medical Center, Amsterdam, the Netherlands,
- 5 Department of Clinical Epidemiology, Biostatistics and Bioinformatics, Academic Medical Center, Amsterdam, the Netherlands

Restorative proctocolectomy with ileal pouch anal anastomosis (IPAA) is associated with tubal factor infertility in female patients. [1,2] Different studies have shown less adhesion formation after laparoscopic colectomy. [3,4] The relation between laparoscopic pouch surgery and fertility, however, has not been studied so far. The aim of this study was to assess the impact of a laparoscopic approach on female fecundity in ileoanal pouch surgery.

For this purpose we conducted a cross-sectional study in three university hospitals in the Netherlands and in Belgium. Female patients were eligible for inclusion if they were older than 18 years at the time of the study, and had undergone IPAA under the age of 41. We sent them a questionnaire addressing medical and fertility history. The primary endpoint was time to first spontaneous pregnancy after IPAA. Of 179 eligible patients, 160 (89%) returned the questionnaire. Following IPAA, 50 (31%) patients attempted to conceive. Of these, 23 (46%) had undergone open and 27 (54%) had undergone laparoscopic IPAA. Patient characteristics were similar in both groups. Indications for surgery were ulcerative colitis (UC) in 37 patients, familial adenomatous polyposis (FAP) in 12 patients and colonic ischaemia in one patient. A Kaplan-Meier survival function was plotted for time to first spontaneous pregnancy and showed a higher pregnancy rate laparoscopic IPAA (log-rank p=0.023). Subsequent survival analysis for the subgroup of all patients with UC (n=37), also showed a higher pregnancy rate for the laparoscopic group (log-rank p=0.033). In conclusion, pregnancy rates are significantly higher after laparoscopic IPAA. This makes the

laparoscopic approach the method of choice in young women.

**WILLEM BEMELMAN**  
S-ECCO Committee Member

**SANNE BARTELS**

### References

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3. Indar AA, Efron JE, Young-Fadok TM. Laparoscopic ileal pouch-anal anastomosis reduces abdominal and pelvic adhesions. *Surg Endosc* 2009; 23(1):174-177.
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# ECCO Country Membership



ECCO is honoured to embrace 31 Country Members in 2012 - the driving force and ambassadors of ECCO.

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# ECCO Educational Workshops – where we have been so far...

-  **1<sup>st</sup> ECCO Workshop**  
Zagreb, **Croatia** - November 10, 2007
-  **2<sup>nd</sup> ECCO Workshop**  
Vienna, **Austria** - December 15, 2007
-  **3<sup>rd</sup> ECCO Workshop**  
Kaunas, **Lithuania** - May 10, 2008
-  **4<sup>th</sup> ECCO Workshop**  
Athens, **Greece** - September 13, 2008
-  **5<sup>th</sup> ECCO Workshop**  
Warsaw, **Poland** - September 26, 2008
-  **6<sup>th</sup> ECCO Workshop**  
Istanbul, **Turkey** - November 8, 2008
-  **7<sup>th</sup> ECCO Workshop**  
Oporto, **Portugal** - November 15, 2008
-  **8<sup>th</sup> ECCO Workshop**  
Haifa, **Israel** - May 5th, 2009
-  **9<sup>th</sup> ECCO Workshop**  
Cluj Napoca, **Romania** - June 17, 2009
-  **10<sup>th</sup> ECCO Workshop**  
Oslo, **Norway** - September 4, 2009
-  **11<sup>th</sup> ECCO Workshop**  
Moscow, **Russia** - September 17, 2009
-  **12<sup>th</sup> ECCO Workshop**  
Belgrade, **Serbia** - October 14, 2009
-  **13<sup>th</sup> ECCO Workshop**  
Sao Paulo, **Brazil** - June 19, 2010
-  **14<sup>th</sup> ECCO Workshop**  
Donetsk, **Ukraine** - September 17, 2010
-  **15<sup>th</sup> ECCO Workshop**  
Budapest, **Hungary** - September 18, 2010
-  **16<sup>th</sup> ECCO Workshop**  
Riga, **Latvia** - October 9, 2010
-  **17<sup>th</sup> ECCO Workshop**  
Galway, **Ireland** - October 15, 2010
-  **18<sup>th</sup> ECCO Workshop**  
Sofia, **Bulgaria** - November 11, 2010
-  **19<sup>th</sup> ECCO Workshop**  
Dubai, **UAE** - April 29, 2011
-  **20<sup>th</sup> ECCO Workshop**  
Helsinki, **Finland** - August 26, 2011
-  **21<sup>st</sup> ECCO Workshop**  
Opatija, **Croatia** - September 17, 2011
-  **22<sup>nd</sup> ECCO Workshop**  
Cordoba, **Spain** - November 12, 2011
-  **23<sup>rd</sup> ECCO Workshop**  
Naples, **Italy** - December 1, 2011



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# Young ECCO (Y-ECCO)

## Dear Colleagues,

Welcome back to the Y-ECCO News pages! In this issue, Franco Scaldaferrri and Marjolijn Duijvestein present the **preliminary results of the Y-ECCO survey** that we performed in Barcelona. Your opinion is very important to us and we take your remarks seriously. In the upcoming months we shall address your suggestions in the Y-ECCO Committee and work on improving our programme. We shall keep you updated. We have **elections** coming up. Two seats will

be available on the Y-ECCO Committee as of February 2013. Every Y-ECCO Member can apply and the positions will be allocated on a competitive basis. We would like to encourage you all to send in your applications and take the opportunity to participate in Y-ECCO activities. A call for applications will be sent out shortly. To date, 20 Y-ECCO Members have published a **literature review** in ECCO News. Fuelled by your ongoing interest and the positive feedback that we have received, we have expanded this section

to five articles in the current issue. Not only does the section provide you with an opportunity to state your opinion on a timely and relevant article, but you can also present yourself and your interests. If you would like to submit a review, please contact [ecco@ecco-ibd.eu](mailto:ecco@ecco-ibd.eu). As always, thank you for all you do for Y-ECCO. On behalf of the Y-ECCO Committee,

**FLORIAN RIEDER**  
Y-ECCO Committee Chair

## The viewpoint of Y-ECCO Members – Preliminary results from a survey at the 7th Congress of ECCO

### What do Y-ECCO Members think of Y-ECCO Activities?

At the 7th Congress of ECCO in Barcelona, a survey was performed. Participants of the 5th Y-ECCO Workshop and delegates at the ECCO Congress under the age of 35 were asked to answer a couple of questions and to tell us their opinion and perception of Y-ECCO. In return, a super nice ECCO USB-stick was provided. In total, 120 fellows participated in this survey, of whom 68% were already Y-ECCO Members.



Y-ECCO Questionnaire and USB Stick © ECCO Office

### Y-ECCO Members

Eighty-one Y-ECCO Members (mean age of 31.5 ± 4 years; 56% male, 44% female) participated in the survey. Most were European (91.4%), but some came from non-European countries like Australia, Israel and Canada. The majority joined Y-ECCO in 2009, although some had already joined the Y-ECCO adventure in 2004.

### Y-ECCO Members: What is your current position?

Only ca. 10% of Y-ECCO Members who participated were already gastroenterologists. About half of the participants (52%) were trainees in GI and 20 % were PhD- students. Others were trainees in surgery or in pediatrics, or medical students.

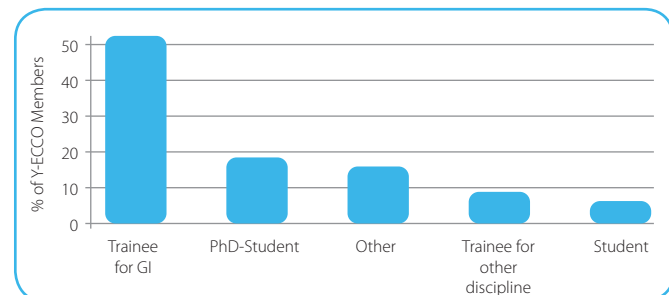


Figure 1: Y-ECCO Members: Current position © Y-ECCO

### Y-ECCO Members: How did you hear about Y-ECCO?

The question on where participants had heard about Y-ECCO yielded a pleasant surprise. Most knew about Y-ECCO because of the positive experiences of colleagues (31%), followed by the head of department (17%) and internet (16%) while 12% knew about Y-ECCO from ECCO News.

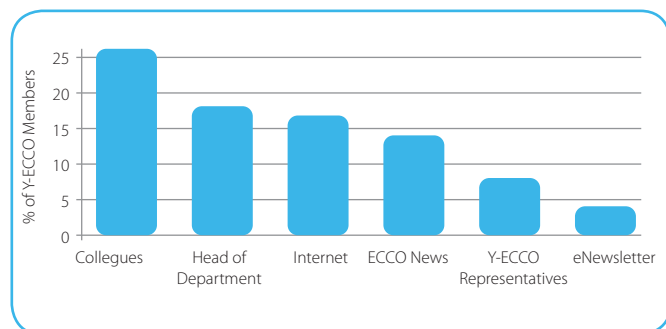


Figure 2: Y-ECCO Members: Information channels © Y-ECCO

### So, what do Y-ECCO Members like about their Y-ECCO Membership?

All options (subscription to JCC, ECCO News, ECCO website, reduced registration fee for the annual ECCO Congress, Y-ECCO co-chairs at the ECCO Congress, Y-ECCO Workshop, participation in educational activities, Y-ECCO Congress Abstract Award, ECCO Fellowships and Grants, ECCO Travel Awards and networking opportunities) received good scores, higher than 3.5 (Scale 1–5), mean score 4 (Scale 1–5). The highest positive score were given to the reduced congress registration fee for Y-ECCO Members, subscription to JCC as well as to ECCO Fellowship and Grants and networking opportunities.

### Comments and suggestions

Unfortunately, we did not receive many open suggestions; however, among the most recurrent requests were a national representative for Y-ECCO Members, a reduced fee for Y-ECCO Membership and more networking events and small group interactions among different subspecialties, including surgeons, pediatricians and basic scientists.

### Non-Y-ECCO Members

Our questionnaire also reached also 39 non-Y-ECCO Members (mean age 31.6 ± 4 years; 40 % male, 60% female); most were European, but some came from countries outside of Europe, including Hong Kong, South Africa and Argentina.

### Non-Y-ECCO Members: What is your current position?

Half of the Non-Members who participated were trainees in GI. Others were already gastroenterologists, PhD- students or trainees in other disciplines such as surgery or in pediatrics.

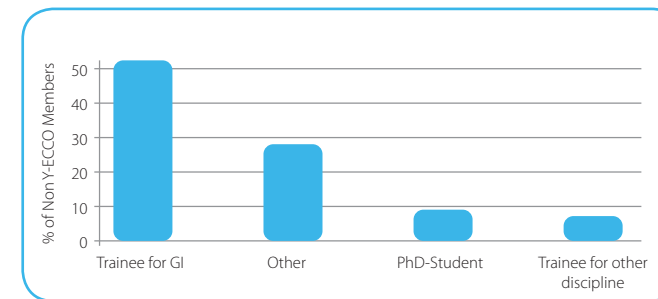


Figure 3: Non-Y-ECCO Members: Current position © Y-ECCO

### Non-Y-ECCO Members: How did you hear about Y-ECCO?

More than 50 % knew Y-ECCO representatives, and when asked how they came to know Y-ECCO, they tended to report that it was through sharing experiences with colleagues. Compared with Y-ECCO Members, more answered that they heard about Y-ECCO via ECCO News or from the internet.

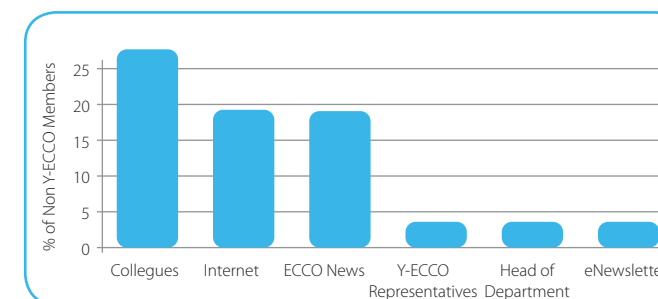


Figure 4: Non-Y-ECCO Members: Information channels © Y-ECCO

### Judgement on Y-ECCO activities

Non-Y-ECCO Members gave a positive overall judgment on Y-ECCO activities, although they were less enthusiastic than Y-ECCO Members (mean score 3.8 Non-Y-ECCO Members vs. 4 Y-ECCO Members). The

activities cited most positively were networking opportunities, ECCO News, subscription to JCC and the reduced ECCO Congress registration fee.

When we asked about their reason for not being a Y-ECCO Member (multiple choice answer possible), about half of them (43%) were interested in becoming a Y-ECCO Member. By contrast, in more than 40% of the cases they replied that the fee is too expensive, while up to 20% answered that they had no time or that they did not know about Y-ECCO Membership.

### Comments and suggestions

Again, non-members made just a few open suggestions, in most cases referring to the need for a national representative for Y-ECCO. Others requested small and more interactive meetings or workshops, including topics relating to basic scientist or pediatric GI. Finally, another important suggestion to emerge from this survey was that in a lot of countries GI fellowship lasts beyond the age limit of 35 years. Consequently this age limit for Y-ECCO Member should be extended.

In the upcoming months we are going to address the issues that were suggested by you in the survey in our committee and we will keep you updated on our progress.

### Summary: What are the most attractive offers from Y-ECCO?

(in order of appearance on the questionnaire)

- Access to ECCO News
- Subscription to JCC – Journal of Crohn's and Colitis
- Information on ECCO website
- Reduced congress registration fee
- Y-ECCO co-chair at annual ECCO Congress
- Y-ECCO Workshop
- Participation in educational activities
- Y-ECCO Congress Abstract Award
- ECCO Fellowship and Grants
- ECCO Travel Awards
- Networking opportunities

**FRANCO SCALDAFERRI**  
**MARJOLIJN DUIJVESTEIN**  
Y-ECCO Committee Members

## Personal picks - Literature reviews from Young ECCO Members

### "Risk of cancer in patients with inflammatory bowel disease and venous thromboembolism: a nationwide cohort study"

Sørensen GV, Erichsen R, Sværke C, Farkas DK, Sørensen T. *Inflamm Bowel Dis* 2012 Jan 12. (Epub ahead of print)

Inflammatory bowel disease (IBD) is a well-known risk factor for thromboembolic events. There is clear evidence in the literature indicating a significant correlation between coagulation and inflammation

in Crohn's disease and ulcerative colitis, leading to an increased risk for venous thromboembolism (VTE) [1,2]. The association between VTE and malignancy has also been recognised; indeed, it has now been widely accepted for more than a century. In recent years, there has been increasing evidence that thromboembolic complications commonly occur before a cancer is diagnosed, and that primary VTE might be a useful marker of an occult tumour [3].

In contrast to primary VTE, the role of secondary VTE as a suitable tool to predict the onset of cancer is still unknown. It remains controversial whether thromboembolic complications occurring in patients with secondary VTE (i.e. in patients with known risk factors such as IBD) can also be used as a marker of an occult tumour. A better understanding of the correlation between IBD and VTE is required to clarify the usefulness of VTE in detecting hidden cancers in patients with IBD.

Sørensen et al. performed a population-based nationwide cohort study with the aim of examining the cancer risk after VTE in patients with IBD. The authors linked the Danish National Registry of Patients (DNRP) with the Danish Cancer Registry (DCR). This led to the inclusion of all patients discharged from Danish non-psychiatric hospital departments since 1977, as well as all hospital outpatients and emergency room visits since 1995. The expected national cancer incidence was determined on the basis of the national cancer data for the Danish population since 1943. The enrolled patients with IBD were followed from their VTE diagnosis date until cancer diagnosis, death or study end-date. For statistical analysis, a standardised incidence ratio (SIR) – the ratio of the observed number of cancers to the expected number of cancers – was used to measure the association between VTE and cancer in patients with IBD. 95% confidence intervals were calculated under the assumption that the observed number of cancers in a specific category would follow a Poisson distribution. A total of 895 IBD patients with VTE were followed for a total of 5,290 person-years. During the first year of follow-up, 28 patients were diagnosed with cancer, corresponding to a 1-year absolute risk of 3.1% and to a SIR of 3.2. In the second and in subsequent years, 61 cancers were diagnosed while 50.6 cancers were expected, corresponding to an overall SIR of 1.2.

#### Risk for colorectal neoplasia in patients with colonic Crohn's disease and concomitant primary sclerosing cholangitis

Braden B, Halliday J, Aryasingha S, Sharifi Y, Checchin D, Warren BF, Kitiyakara T, Travis SPL, Chapman RW  
Clinical Gastroenterology and Hepatology. 2012;10:303-8

#### Introduction

Several studies have shown that patients with inflammatory bowel disease (IBD) have an increased risk of developing colorectal cancer (CRC) [1-3]. Among IBD patients, greater duration of disease, extent of disease and severity of disease are all associated with higher risks of CRC.

Primary sclerosing cholangitis (PSC) is characterised by bile duct inflammation, fibrosis and stricturing that may lead to cirrhosis, hepatic failure and cholangiocarcinoma. A large proportion of PSC patients have co-existing ulcerative colitis (UC), with a smaller proportion having Crohn's disease (CD) with colonic involvement. It is well documented that patients with UC and concomitant PSC have a significantly higher risk of developing CRC, with an adjusted relative risk from 3.1 to 6.9 [4-5].

Little is known, however, about whether PSC also increases the risk of developing CRC in patients with colonic CD. To address this issue, Braden et al. conducted a retrospective analysis on the occurrence of CRC or colorectal dysplasia in patients with colonic CD with and without PSC (n=149), in patients with indeterminate colitis and PSC (n=11) and also in patients with UC with and without PSC (n=222).

#### What are the relevant findings?

A large proportion of patients with PSC and CD had macroscopic pancolitis (82%). A similar finding was also observed in PSC and UC patients (89%) and indeterminate colitis patients (73%) as well as in CD (90%) and UC (75%) patients without PSC. After a median follow-up of 11 years, the cumulative incidence of development of nonadenomatous-like dysplasia or CRC was 7.5% (9/120) in patients with PSC and UC and 2.9% (3/102) in patients with UC alone. The odds ratio for PSC as a risk factor for developing nonadenomatous-like dysplasia or CRC was 2.7 (95% CI 0.7-10.1) in UC.

In contrast, among the colonic CD patients with PSC,

#### Conclusion

The authors concluded that VTE in IBD patients is not only a consequence of the disease, but might also be a useful tool to detect occult cancer. They finally suggested that the same diagnostic work-up guidelines should be applied in IBD patients with VTE as in non-IBD patients suffering from primary VTE.

#### Summary

In summary, this study was the first trial to determine cancer risk in patients with IBD and VTE. Although the correlation between VTE and cancer is generally accepted, and IBD has also been shown to be a significant risk factor for thromboembolic events, the risk of a cancer in IBD patients subsequent to VTE detection is still unknown [1-3]. The authors have finally demonstrated that the risk of malignancy in IBD patients with VTE is the same as in non-IBD patients with thromboembolic complications. Thus, IBD patients with VTE should undergo the same diagnostic procedures to detect hidden cancers as non-IBD patients suffering from primary thromboembolism. Limitations of this study included the low number of cancer cases and the potential 'misclassification' of VTE due to the diagnosis coding system used for the registry. The strength of the study resides in its population-based design with complete follow-up available

no CRC case was observed and only one of the 35 patients had an adenomatous polyp (tubular adenoma) with low-grade dysplasia after a median follow-up of 10 years. Of the patients with CD alone, 3/114 had dysplasia or cancer. The odds ratio for PSC as a risk factor for developing nonadenomatous-like dysplasia or CRC in colonic CD was 1.64 (95% CI 0.14-18.7).

Nonadenomatous-like dysplastic lesions and CRC had a trend to occur more frequently in patients with UC and PSC (9/120) than in patients with CD and PSC (0/35; p=0.07). It was also observed that the majority of CRCs were located predominantly on the left side of the colon (8/13 cases). PSC-related mortality showed a tendency to occur more frequently in patients with UC (33%) than in those with CD (17%; p=0.33).

#### Why is this study relevant and important?

The presented manuscript clearly shows that there is no increased risk of colorectal neoplasia in patients with PSC and colonic CD compared to colonic CD alone. This is in contrast to the findings in patients with PSC and UC. The aetiopathogenesis of the increased risk of CRC in patients with UC and PSC is unknown. However, bile acids are thought to play an important role as CRC in UC with concomitant PSC occurs predominantly in the right colon [6]. In addition, the use of ursodeoxycholic acid has been shown to be an effective chemoprotective agent for CRC in patients with UC and PSC [7]. Interestingly, in this cohort the majority of patients with PSC were treated with ursodeoxycholic acid but the CRC was observed predominantly in the left-sided colon.

This finding also raises the issue of the need for and the appropriate frequency of surveillance colonoscopy or flexible sigmoidoscopy in colonic CD patients with PSC since only one out of 35 patients developed dysplastic tubular adenoma with low-grade dysplasia during a follow-up of 10 years. This is in contrast to the findings of Rasmussen et al., who reported two CRC cases in nine colonic CD patients with PSC during a follow-up of 15 years [8].

All in all, this study demonstrates that patients with colonic CD and concomitant PSC have no increased risk of developing colorectal neoplasia, which is in contrast to patients with UC and PSC. However, further prospective studies that include the assessment of classical risk factors associated with CRC as well

for all patients, and it represents a useful first step in correlating IBD, venous thromboembolism and cancer risk.

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Reingard Platzer @ Reingard Platzer

as medications used in patients with PSC, such as mesalamine, immunosuppressants and biologics, are needed to confirm or refute the findings.

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#### Recombinant human erythropoietin in patients with inflammatory bowel disease and refractory anemia: A 15-year single-center experience

Katsanos KH, Tatsioni A, Natsi D, Sigounas D, Christodoulou DK, Tsianos EV  
*J Crohns Colitis*. 2012;6(1):56-61.

#### Introduction

In this descriptive retrospective single-centre study, Katsanos and colleagues searched the records of all their IBD patients receiving erythropoietin (EPO) therapy between 1994 and 2009. The list included 26 IBD patients (16 UC, 10 CD) with refractory disease in need of immunomodulators (65%) or infliximab (27%). These subjects were receiving EPO therapy because their anemia was not responding to IV iron therapy, because of a poor tolerance of the therapy, or because of a severe adverse reaction, to IV iron therapy. The paper summarises 15 years of experience of a single centre with EPO therapy.

#### What this paper is about

Anemia, which places a great strain on affected patients' quality of life and ability to work, is present in one in five IBD outpatients [1], while one-third of IBD patients suffer from recurrent anemia [2]. IBD-associated anemia involves a combination of chronic iron deficiency

and anemia of chronic disease due to intestinal inflammation. The accompanying overproduction of cytokines is suspected of contributing to chronic disease anemia, as well as of inducing a relative deficiency of EPO. Hence, EPO therapy is an effective, yet expensive, option that is reserved for the treatment of anemia refractory to IV iron therapy. Katsanos and his colleagues assessed short- and long-term responses to EPO therapy both 3, and then 12 months following the end of the first EPO cycle. They found that more than 50% of the patients achieved Hb >12 g/dL, while 85% responded either fully or partially to EPO therapy (Hb increase at least 1 g/dL). Furthermore, the number of blood transfusions was reduced after EPO therapy and no adverse events were observed. However, careful monitoring of peripheral blood parameters was needed, and many patients required additional EPO therapy (27%) or IV iron therapy (39%) to avoid the recurrence of anemia.

#### Conclusion

This study once again underlines the need for further research in this field. In line with previous studies, it demonstrates that EPO treatment is safe and, together with the proper treatment of intestinal inflammation, is effective in treating refractory anemia. This centre used one of many possible approaches

#### The diagnostic accuracy of fecal calprotectin during the investigation of suspected pediatric inflammatory bowel disease

Henderson P, Casey A, Lawrence SJ, Kennedy NA, Kingstone K, Rogers P, Gillet PM, Wilson DC  
*Am J Gastroenterol* advance online publication, 28 February 2012

#### Introduction

Diagnosis of IBD is still made by endoscopic assessment and histology. Due to long waiting lists for endoscopy, a procedure considered invasive and uncomfortable, and the rising incidence of IBD in children, a good screening tool is necessary. Calprotectin is a calcium-binding protein found in neutrophil granulocytes. Measured in stool samples, it is a stable marker of mucosal inflammation. Similar to the development of new drugs, diagnostic test development goes through several phases [1]. In phase I of the development of a calprotectin test, researchers show that patients with IBD have different test results from healthy individuals. In phase II studies, researchers compare faecal calprotectin (FC) levels in preselected groups of healthy individuals and individuals with severe IBD and show that the test can discriminate between them under ideal circumstances. Phase III studies evaluate whether FC can achieve such discrimination in routine paediatric practice. In this type of study, patients in whom it is clinically reasonable to suspect IBD are consecutively enrolled. All patients are included, regardless of lost results or indeterminate diagnosis. In phase II studies, the same reference standard is used for patients with and without IBD, whereas phase III studies more often use different standards for patients with and without the disease.

#### What is this paper about and what are the key findings?

This paper concerns a retrospective case-control study that evaluated the diagnostic accuracy of FC in suspected IBD compared with six commonly used blood parameters and endoscopy as the reference tests. The study patients, in whom FC was measured as part of the initial diagnostic work-up, were identified from a departmental database from all incident cases of paediatric IBD (PIBD) diagnosed according to the PORTO criteria since August 1997. This search resulted in 91 patients with IBD and 99 non-IBD (control) patients during the 6-year period of FC data collection from 2005 to 2010.

The following key findings were reported in this article:

- (1) Children with IBD have significantly elevated FC at diagnosis compared with controls undergoing endoscopy. The authors calculated the diagnostic accuracy for different cut-off levels. As mentioned in other articles, using the manufacturer's cut-off of >50 µg/g results in high sensitivity (0.98) but low specificity (0.44) for IBD.
- (2) FC levels in children with IBD are not influenced by sex, age, IBD type or disease location. In the examined IBD patients there was no difference in the median FC levels between those with upper intestinal CD location and those without. CD patients with isolated colonic or ileocolonic disease had a similar median FC level compared with those with UC and IBD-U combined.
- (3) FC performs better than commonly used blood parameters as a diagnostic biomarker during the evaluation of children with suspected IBD. The area under the curve (AUC) was greater than all six blood parameters at 0.93 (95% CI 0.89-0.97) and significantly higher than the AUC for ESR (P=0.011), CRP (P=0.006), total white cell count (P<0.001), haemoglobin (P<0.001) and platelet count (P<0.001), although not significantly greater than that for albumin (P=0.374).

#### Critical remarks

This evaluation of the diagnostic accuracy of FC is a phase II study. There was no inclusion of consecutive patients in whom it was clinically justified to suspect IBD. The authors selected retrospectively all patients who had FC and upper and lower endoscopy, not those who fulfilled the criteria for suspicion of gut inflammation. So they could not formulate the answer to the hypothesis stated in the introduction: "We therefore hypothesized that the diagnostic accuracy of FC in suspected PIBD would be equivalent to endoscopy and superior to six commonly used blood parameters." The authors could not conclude whether diagnostic accuracy is equivalent to endoscopy because they did not take into account the number of patients who had an elevated calprotectin without endoscopic evaluation. Hence, the measures of diagnostic accuracy of FC are overestimated. The authors mentioned a long waiting time for endoscopic evaluation. One can therefore assume that only those patients with high clinical suspicion for IBD went on to have endoscopic evaluation. This could have led to selection bias.

to patients not responding to initial EPO dosing, and recommendations for a "target Hb level" for EPO therapy, as well as optimal dosing, dosing modifications and effect monitoring, are yet to be established.

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Johan Burisch © ECCO Photographer

The time period between the index test (FC) and the reference standard (endoscopy) could be up to 6 months. This is a rather long period considering IBD is a disease with exacerbations and spontaneous remissions. The same remark applies evaluation of the blood results within 6 months of endoscopy. Over- or underestimation of the diagnostic accuracy of FC could have resulted. A valid reference test was used but the index test and reference test were not independently judged. The authors mentioned this in the discussion but although none of the endoscopies were annulated, some patients with high FC and low clinical suspicion were not endoscopically evaluated and could have had a delay in diagnosis, with possible overestimation of the sensitivity. It is not clear from the article whether the decision in respect of the reference test was independent of the results of the index test for all patients.

#### Conclusion/What is of interest in this study

This study confirms in a large paediatric study population that FC discriminates IBD under ideal circumstances. What this study adds is that FC at diagnosis of IBD is not influenced by age, sex, PIBD type or disease location. The diagnostic accuracy of the commonly measured blood parameters (ESR, CRP, total white cell count, haemoglobin and platelet count) was low in a study population of children with a high clinical suspicion of IBD.

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Els Van de Vijver © UZA, Mr Jan Locus

### Validation of the Capsule Endoscopy Crohn's Disease Activity Index (CECDAI or Niv score): a multicenter prospective study

Niv Y, Ilani S, Levi Z, Hershkowitz M, Niv E, Fireman Z, O'Donnell S, O'Morain C, Eliakim R, Scapa E, Kalantzis N, Kalantzis C, Apostolopoulos P, Gal E.

Endoscopy 2012 Jan;44(1):21-6. Epub 2011 Nov 28.

#### Introduction

The concept of deep remission in Crohn's Disease (CD) is being increasingly recognised as a cornerstone predictor of clinical behaviour and prognosis [1,2]. Indeed, mucosal healing has been shown to be associated with increased rates of clinical remission, fewer hospitalisations and fewer abdominal surgeries [1]. Therefore, video capsule endoscopy (VCE) has become an attractive non-invasive tool to assess small bowel mucosal damage in patients with CD [3]. However, none of the available VCE scoring indices used to diagnose and measure small bowel involvement in CD has been prospectively validated.

#### What this paper is about

In this multicentre, multinational (four centres in Israel, one in Greece and one in Ireland), double-blind, prospective, controlled study [4], the authors enrolled 62 consecutive patients with isolated small-bowel CD, 50 of whom were able to finish the study protocol. The aim was to prospectively validate the use of the Capsule Endoscopy Crohn's Disease Activity Index (CECDAI or Niv score) [5] in the assessment of small bowel mucosal disease activity using VCE. The CECDAI was designed to evaluate three main parameters of CD: inflammation (A), extent of disease (B) and stricture (C), all graded on a numerical scale in both the proximal and the distal segment of the small bowel. These two segments were defined by equally dividing the small bowel transit time. The final score was calculated by adding the two segmental scores: CECDAI = proximal [(A1xB1)+C1] + distal [(A2xB2)+C2] (Table 1). In this index, villous appearance and ulcers are considered to be opposite extremes of a wide range of inflammation rather than independent variables, as was the case in the Lewis Score [6-8]. Also, the number of lesions is not important for calculating the CECDAI, because when different inflammatory lesions are identified in the same bowel segment, only the more severe lesion is considered.

The primary end point of the study was to validate the CECDAI score. The secondary end points were to evaluate the correlation between CECDAI and both the Crohn's Disease Activity Index (CDAI) and Inflammatory Bowel Disease Quality of Life Questionnaire (IBDQ).

The mean age of the study population was 39.44±16.14 years and 28 (56%) were women. Twenty-three patients (46%) were in clinical relapse (CDAI >150).

Looking at the results, the interpretation of the CECDAI showed a good correlation between endoscopists from the different study centres, reaching statistical significance, with  $r=0.767$  (range 0.717–0.985; kappa 0.66;  $P<0.001$ ). A significant correlation was demonstrated between the calculation of the CECDAI by the individual site investigators and that performed by the principal investigator. Overall, the distal scores were higher than the proximal scores: 6.70±5.04 vs 2.76±3.49 (difference 3.94, 95% confidence interval [CI] 2.59–5.29;  $P<0.0001$ ), and 6.50±5.24 vs 3.32±4.17 (difference 3.18, 95% CI 1.67–4.69;  $P<0.0001$ ). Proximal small bowel was involved in up to 62% of patients. No correlation with the CECDAI was found for CDAI or IBDQ or any of their components.

#### Conclusion

The authors validated a new user-friendly score for VCE, the CECDAI, and recommend its use in controlled trials and/or regular follow-up of patients with small bowel CD. Although a relatively small number of patients were enrolled in the study, it had the statistical power to validate the score in everyday clinical practice. In this study, VCE diagnosed proximal small bowel involvement in the majority (up to 62%) of patients, revealing significant lesions out of the reach of the standard colonoscope. As endoscopic remission has been associated with better outcomes and prognosis in CD [1,2], the CECDAI may become particularly valuable for use in a longitudinal way, to assess response of patients to a given medical therapy, comparable to the Crohn's Disease Endoscopy Index Score (CDEIS) used in drug trials for ileocolonic disease [9]. However, as the authors underline, the CECDAI has the drawback that it can only be applied to patients with isolated small bowel CD with no colonic involvement.

Similarly to several previous trials, this study could not demonstrate a positive correlation between the endoscopic score and clinical indices. This may be due to the fact that symptoms such as diarrhoea, fatigue and abdominal pain are usually multifactorial and not necessarily associated with the presence of significant endoscopic lesions.

Finally, it must be underlined that, like other endoscopic activity scores, the CECDAI cannot by itself diagnose CD as it measures mucosal changes and the degree of mucosal inflammation regardless of aetiology. It has no discriminatory ability in differentiating CD from other diseases such as non-steroidal anti-inflammatory drug enteropathy, radiation enteritis, coeliac disease, lymphoma, vasculitis and/or ischaemia, and it seems unlikely that a threshold for differential diagnosis might be determined. Moreover, up to 10% of healthy individuals may present small bowel mucosal lesions of unknown clinical significance [10], and thus it is crucial to interpret the endoscopic score in the light of each individual clinical context.

To summarise, this new objective and reproducible endoscopic score standardises the assessment of small bowel inflammatory activity and may become a useful tool in future research into small bowel CD.

A. Inflammation score	
0	None
1	Mild to moderate edema / hyperemia / desquamation
2	Severe edema / hyperemia / desquamation
3	Bleeding, exudate, aphthae, erosion, small ulcer (<0.5cm)
4	Moderate ulcer (0.5 - 2cm), pseudopolyp
5	Large ulcer (>2cm)
B. Extent of disease score	
0	No disease
1	Focal disease (single segment)
2	Patchy disease (2-3 segments)
3	Diffuse disease (more than 3 segments)
C. Stricture score	
0	None
1	Single-passed
2	Multiple-passed
3	Obstruction (non-passage)

Table 1: Capsule Endoscopy Crohn's Disease Activity Index (adapted from Niv Y et al, 2012 [4]) (Source: Bruno Rosa)

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# JOURNAL OF CROHN'S & COLITIS

International Journal Devoted to Inflammatory Bowel Diseases  
Official Journal of the European Crohn's and Colitis Organisation



Volume 6, issue 5

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June 2012

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# Special article: ECCO Individual Membership 2012

Individual membership was introduced in 2008.

## Continuing growth in membership numbers

As of April 2012, ECCO has over 1,800 registered individual members (Total 1,822 Members as of May 3, 2012), with numbers increasing each year.

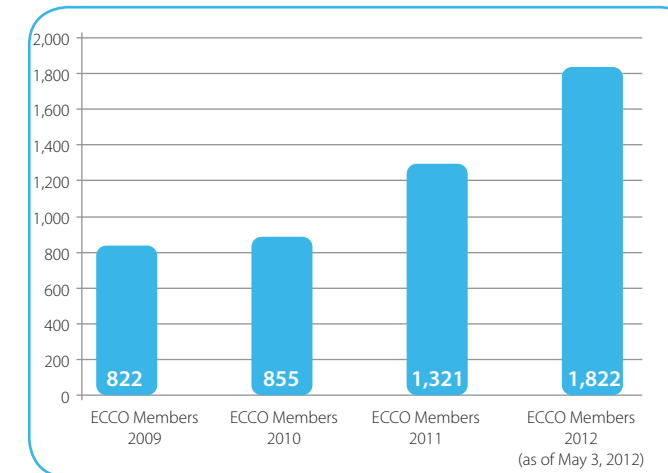


Figure 1: ECCO individual membership numbers, 2009 to 2012 © ECCO Office

## Membership categories

ECCO offers two different categories of individual membership:

- Regular Membership/Y-ECCO Membership (EUR 100/year)
- IBD nurse Membership (for IBD nurses and affiliate professions) (EUR 25/year)

## Regular Members

Regular Membership is available for clinicians, physicians and scientists with a special interest in IBD (completed university degree).

## Y-ECCO Members

Y-ECCO Membership may be attractive for young fellows, researchers and trainees in the field of gastroenterology who are below the age of 35. In addition to the same benefits as are offered to Regular Members, Y-ECCO Membership includes activities targeted specifically at young and/or future gastroenterologists, such as workshops on career building.

## IBD nurse Members

N-ECCO Membership is open to nurses and affiliate professions and includes access to educational events and activities especially targeted at IBD nurses.

Membership category	No.
Regular Members	1,170
Y-ECCO Members	338
IBD nurse Members/Affiliate professions	314
<b>Total N° of Individual Members</b>	<b>1,822</b>

Table 1: ECCO individual membership statistics per category, 2012 (as of May 3, 2012) © ECCO Office

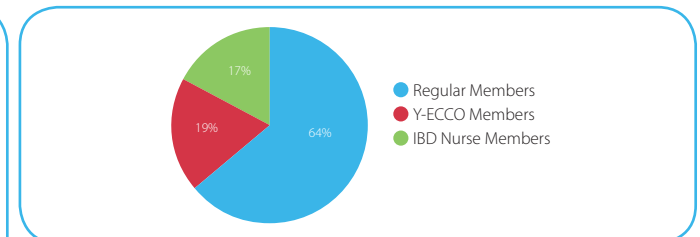


Figure 2: ECCO individual membership statistics per category, 2012 (as of May 3, 2012) © ECCO Office

## Diversity

ECCO is proud to welcome members from 65 different countries (as of May 3, 2012).



Figure 3: Diversity of individual members shown on world map (as of May 3, 2012) © ECCO Office

## "Top 25 countries" individual membership (absolute numbers)

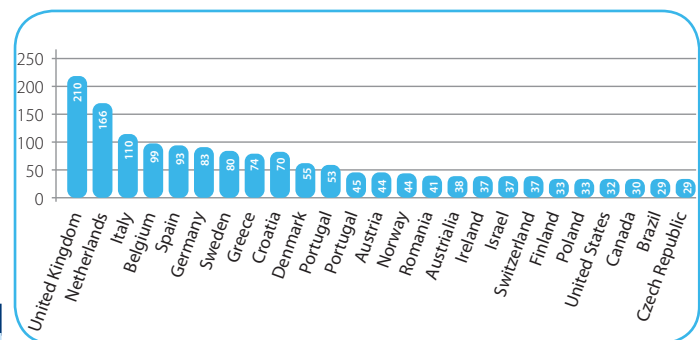


Figure 4: ECCO individual membership statistics per country, 2012 (as of May 3, 2012) © ECCO Office

In order to become an ECCO Member, please fill in a membership application form or register online ([www.ecco-ibd.eu](http://www.ecco-ibd.eu)). For questions concerning individual membership, contact the ECCO Office at [ecco@ecco-ibd.eu](mailto:ecco@ecco-ibd.eu) or +43-(0)1-710 22 42.

# Special article: ECCO National Representatives' Survey 2012

The involvement of ECCO Country Members and their National Representatives are vital to the development of ECCO. ECCO National Representatives can be considered the driving force and ambassadors of ECCO – a role which brings recognition, but also tasks and responsibilities.

First of all, ECCO would like to thank all (current and past) National Representatives for their efforts and willingness to commit themselves to our mission. ECCO's mission is to improve the care for patients with IBD across Europe. The vigour of ECCO comes from its ethos of providing opportunity for new and young people. **National Representatives are a key component of ECCO's interaction with its members and their societies in different countries** to help ECCO achieve its goal of improving care – through education of advanced trainees, dissemination of practice guidelines through workshops, facilitating research through Grants and Fellowships and interacting with national patient-based organisations. The Governing Board relies on the National Reps to be the **liaison to the National Societies as well as the individual members of ECCO** within their respective country. With roles come responsibilities. A survey of National Reps after the 7<sup>th</sup> Congress of ECCO in Barcelona in 2012 enabled the specific roles, expectations and responsibilities to be defined. Thirty out of 31 ECCO Country Members participated in the survey and answers came from 48 out of 62 ECCO National Reps. ECCO very much values their views and contributions, but the 77% response rate suggests that there is work to be done to engage with all National Reps, who are your representatives in ECCO.

The Survey included four principal questions, with several components:

- What do you believe are appropriate tasks for an ECCO National Rep?
- What do you believe are appropriate responsibilities for an ECCO National Rep?
- What opportunities within ECCO would you welcome and be prepared to commit to?
- What are your views on specific tasks within ECCO?

The answers have defined the roles, responsibilities and expectations of National Reps, with the percentage agreement given in brackets:

## Roles of an ECCO National Rep

1. To elect the President- Elect, Treasurer and Secretary of ECCO in the General Assembly (100%)



ECCO Country Members 2012 © European Crohn's and Colitis Organisation

2. To promote individual membership and the profile of ECCO in their country (100%)
3. To promote opportunities in ECCO to IBD specialists and trainees (98%)
4. To involve local partners (corporate, national authorities, national patient organisations) (96%)
5. To support ECCO in promoting the ECCO Congress in your country (96%)

## Responsibilities of an ECCO National Rep

1. To select two top trainees from their country to attend the Advanced Course (96%)
2. To attend the Strategic Council meeting and General Assembly (100%)
3. To ensure that the Country Membership fee (which supports the Advanced Course) is paid to ECCO in a timely manner (91%)
4. To inform the ECCO Office of the process by which NRs are selected in their country and send details of newly elected NRs to the ECCO Office (98%)
5. To inform the ECCO Office of the process by which

top trainees are selected to represent their country by attendance at the Advanced Course (89%)

## Expectations by ECCO of National Reps

1. To be themselves a member of ECCO in good standing (in other words, paid up!) (100%)
2. At the ECCO Congress, NRs should not attend any meeting or symposium that conflicts with the Strategic Council or General Assembly meetings on the Thursday evening (100%)
3. If an NR does not recommend trainees for the Advanced Course, or is unable to attend two out of three meetings of the Strategic Council, then that country's members will be informed, so that they have the opportunity to consider whether the NR is too busy to fulfil the role in their interests (87%)
4. Supporting ECCO and the annual congress may be achieved by provide dates of national meetings to ECCO (to receive promotional material on ECCO to be distributed), placing a banner or link to the programme on their national society website, or mailings to the local database (94%)

5. Promoting opportunities to trainees includes ECCO Fellowships, Grants and Travel Awards, abstract and JCC submission, promotion of committee membership and guideline participation, most easily achieved through a Trainees' section of the national Gastroenterology society or email to the local database of members for dissemination to trainees (94%). To encourage applications for travel awards from Central and Eastern Europe three out of five travel awards will be offered to specific countries through National Representatives in May each year. In 2013 this will be Bulgaria, Romania and Turkey. Every country can and is encouraged to apply for one of the two open travel awards.

## Opportunities during and after a term as National Rep

1. Host an ECCO Workshop in your country, best aligned to a National Gastroenterology meeting (78%; note the criteria on [www.ecco-ibd.eu](http://www.ecco-ibd.eu) and contact the EduCom Chair)
2. Write a profile of IBD in your country for ECCO News (91%; contact the ECCO Office and/or Secretary)
3. Propose a young trainee for a Travel Award (note the criteria on [www.ecco-ibd.eu](http://www.ecco-ibd.eu) and contact the SciCom Chair)
4. Create a Country Profile Poster to be displayed at the ECCO Congress (78%; a good task for a specialist trainee!)
5. Suggest names of academic clinicians and scientists from their country for abstract review (91%; annually, by September, to congress management, [ecco-congress@ecco-ibd.eu](mailto:ecco-congress@ecco-ibd.eu)), in addition to being nominated to score abstracts (87%)
6. Be 'the face of ECCO' at the ECCO booth during the coffee breaks at the Congress (61%; contact congress management, [ecco-congress@ecco-ibd.eu](mailto:ecco-congress@ecco-ibd.eu))
7. Co-chair poster rounds at the ECCO Congress (87%)
8. Stand as a committee member for ECCO after a term as National Rep (89%; find out about the role from the chair of the appropriate committee and apply when openly advertised)
9. Represent ECCO on a UEG committee (find out about the potential roles through the ECCO Office. Names of departing NRs will be considered by ECCO GB who make the recommendation, but the choice will depend on how much the NR contributed to ECCO)

## Decisions informed by the survey

1. The term of office for a National Representative shall be 3 years
2. The process for selecting NRs will be the choice of that country, commonly being one NR as an ex-officio position as chair of the

IBD society or section and the other elected by ECCO Members of that country. The ECCO Office must be informed of the procedure for electing the country's two NRs and this will be placed on the ECCO Members' website

3. An NR can be re-elected once, but this should be the exception rather than the expectation
4. NRs who have already been in post for >6 years will be expected to stand down and are encouraged to pursue other roles within or on behalf of ECCO.

## So what happens now?

Representing a country as a National Representative is a privilege and brings recognition, but was never intended to be an endorsement by ECCO of a person's standing as an IBD specialist in their country. For this reason there has to be a fixed term of office and change. The roles have been defined, as well as the expectations of ECCO with regard to responsibilities. The position carries electoral power within ECCO, the opportunity of promoting their young members (through selection for the Advanced Course), their country (through ECCO News and profiles) and a responsibility of representing their country to ECCO and ECCO to their country. Change is always awkward, but it is vital to the vigour of ECCO.

Current National Reps have been asked to start the electoral process, if appropriate, as well as the selection process for trainees to attend the Advanced Course and to inform the ECCO Office of the process. In the interests of transparency these processes will be placed on the ECCO Members' website. National Reps will be invited by the ECCO Office and Secretary ([ecco@ecco-ibd.eu](mailto:ecco@ecco-ibd.eu)) to write a profile of IBD care in their country for ECCO News and to identify a suitable person to create a Country Profile Poster about IBD care in their country for the ECCO Congress. This is particularly important for those countries that are smaller than others. ECCO would like to increase representation from Central and Eastern Europe and to help people to achieve that. National Reps act as a conduit not only from ECCO to members in their country, but also from their members and national societies to ECCO.

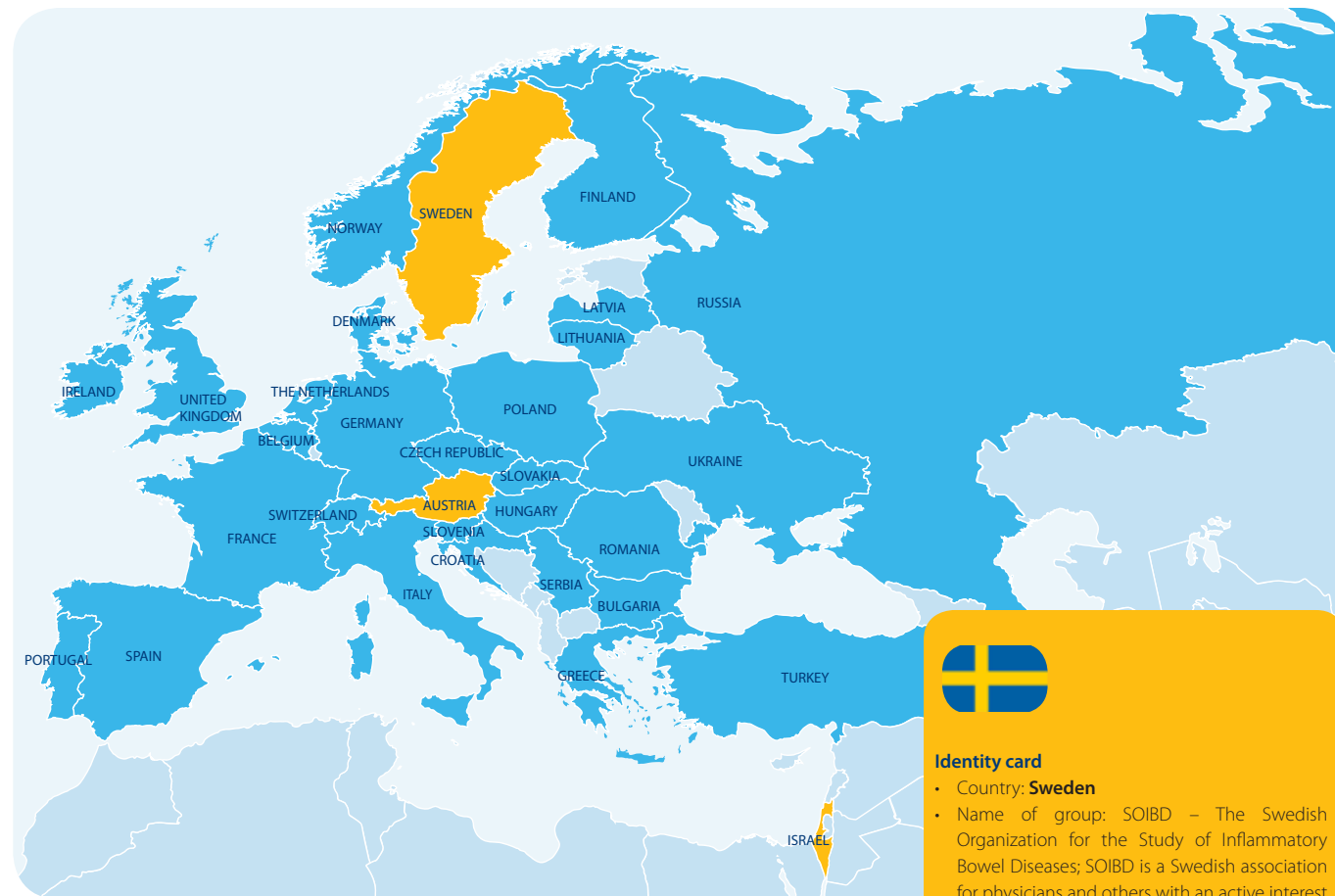
At the end I want to thank all the National Reps who replied to the survey. This has been really helpful in defining the roles, responsibilities and expectations. I also want to add my personal thanks and appreciation for the work which has been done by our National Reps on ECCO's behalf, even though there is more to come!

Austria: Gottfried Novacek, Walter Reinisch  
Belgium: Filip Baert  
Bulgaria: Iskren Kotzev  
Croatia: Silvija Cukovic-Cavka  
Czech Republic: Tomas Douda, Martin Bortlik  
Denmark: Jens Dahlerup  
Finland: Martti Färkkilä, Pia Manninen  
France: Franck Carbonnel  
Germany: Andreas Sturm, Torsten Kucharzik  
Greece: John A. Karagiannis, Epameinondas Tsianos  
Hungary: Peter Lakatos, Tamas Molnar  
Ireland: Laurence Egan, Colm O'Morain  
Israel: Iris Dotan, Selwyn Odes  
Italy: Anna Kohn, Paolo Gionchetti  
Latvia: Juris Pokrotnieks, Jelena Derova  
Lithuania: Limas Kupcinskas  
The Netherlands: Rinse Weersma, Herma Fidler  
Norway: Ingrid Prytz Berset  
Poland: Jaroslaw Regula, Grazyna Rydzewska  
Portugal: Luis Correia, Fernando Magro  
Romania: Adrian Goldis, Mircea Diculescu  
Russia: Elena Belousova, Alexander Potapov  
Serbia: Njegica Jojic, Dino Tarabar  
Slovakia: Miloš Greguš  
Spain: Francesc Casellas, Fernando Gomollon  
Sweden: Hans Strid, Leif Törkvist  
Switzerland: Pierre Michetti  
Turkey: Aykut Ferhat Celik  
Ukraine: Andrey Dorofeyev  
United Kingdom: James Lindsay

On behalf of the ECCO Governing Board,

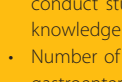
**SIMON TRAVIS**  
ECCO President

# ECCO Country Member Profiles



## Identity card

- Country: **Austria**
- Name of group: Working Party on Inflammatory Bowel Diseases (Working Party IBD) of the Austrian Society of Gastroenterology and Hepatology (ÖGGH)
- Number of active members: Austrian individual ECCO Members: 44; ÖGGH Members: approximately 950
- Number of meetings per year: 3 annual regular meetings; several regional meetings
- Name of president and secretary: Leader of the Working Group IBD: Gottfried Novacek (=first Austrian Nat Rep); Delegate of the leader: Walter Reinisch (= second Austrian National Representative); President of ÖGGH: Peter Knoflach; Secretary of ÖGGH: Clemens Dejaco
- Incidence of IBD in the country (if available): not available; an estimated number of 60,000 to 80,000 patients inferred from hospitalisation data



## Identity card

- Country: **Israel**
- Name of group: Israel IBD Society
- Number of active members: Approximately 50
- Number of meetings per year: 2-3
- Name of president and secretary: President: Yehuda Chowers; Secretary: Eran Israeli
- Incidence of IBD in the country (if available): 9/100,000/year (estimated)



## Identity card

- Country: **Sweden**
- Name of group: SOIBD – The Swedish Organization for the Study of Inflammatory Bowel Diseases; SOIBD is a Swedish association for physicians and others with an active interest in inflammatory bowel disease (IBD) research. The main purposes of the association are to conduct studies and research and to develop knowledge in IBD.
- Number of active members: The members are gastroenterologists, colorectal surgeons and paediatric gastroenterologists from all parts of Sweden. Currently there are 35 members and 10 companies supporting the association. The committee of SOIBD consists of four members. All members in SOIBD are also individual members of ECCO.
- Number of meetings per year: All members meet twice a year. At the meetings, invited lecturers with specialised knowledge in IBD present their research and spread their enthusiasm to the members. Ordinary agenda items, presentation of new members, reports from the working groups and presentation of new/ongoing studies are on the programme at these meetings.
- Name of president and secretary: President: Anders Eriksson; Secretary: Marie Carlson
- Incidence of IBD in the country (if available): The figures are approximate; Ulcerative Colitis, 8-12/100,000/year; Crohn's Disease, 5-9/100,000/year.

## Questionnaire – AUSTRIA

- **How did your national group start?**  
It was founded by Wolfgang Petritsch in 1994.
- **How is your group organised in terms of new members joining the group, meetings, election of president etc.?**
  - Members: All members of the Working Party IBD have to be members of the ÖGGH. The Working Party is an open group and is defined by interest in the field of IBD but not by a special Working Party membership.
  - The three most important regular and annual Austrian IBD Meetings are:
    1. Spring Meeting (1 week after Easter)
    2. Congress of ÖGGH (June): not specific to IBD but includes IBD topics
    3. Symposium on immunosuppression and monoclonal antibodies in IBD (September)
  - The leader of the Working Party IBD is elected by anonymous poll by the members of the ÖGGH. The term of office is 2 years. The leader can be selected for two terms (=4 years). The leader of the Working Party is the first National Representative of ECCO. After his or her 4 years in office, he/she will be the second National Representative for another 2 years to ensure continuity.
  - The second National Representative will be selected at the Spring Meeting (for 2 years).
- **When did your group join ECCO?**  
2001



Members of the Austrian Working Party on IBD (Source: Gottfried Novacek)

- **What are your main areas of research interest?**  
Clinical studies which afford sample sizes not being achieved by single centres.
- **Does your centre or country have a common IBD database or bio bank?**  
Some centres are running a database based on IBDIS.
- **What are your most prestigious/interesting past and ongoing projects?**  
Safety check study, venous thromboembolism, interobserver studies on IBDIS, consensus meetings (anaemia, safety of infliximab, colorectal cancer in IBD etc.), national awareness campaigns.
- **Which ECCO projects/activities is the group currently involved in?**  
ECCO Guidelines
- **What are your aims for the future?**  
Common IBD database and establishment of a network structure between IBD outpatient clinics and community-based gastroenterologists for the management of

- patients (referral IBD centres, other hospitals, physicians etc.).
- **How do you see ECCO helping you to fulfil these aims?**  
Facilitating collaboration with IBD Working Parties of other countries.
- **What do you use ECCO for? Network? Congress? How do you use the things/services that ECCO has to offer?**  
ECCO Congress; ECCO Guidelines; use of the network of ECCO to collaborate with colleagues within Europe – particularly the exchanges among young colleagues are of importance in developing a deeper basis for IBD.

**GOTTFRIED NOVACEK, WALTER REINISCH**  
ECCO National Representatives, Austria

## Questionnaire – ISRAEL

- **How is your group organised in terms of new members joining the group, meetings, election of president etc.?**  
Members join according to their interest. There are no specific inclusion criteria except for being an Israeli gastroenterologist. There are 2-3 meetings/year, focussing on updates, education and specific activities. Elections are through the Israeli Gastroenterology Association.
- **When did your group join ECCO?**  
Israel became an official ECCO Country Member in 2003. Israeli gastroenterologists join ECCO on an individual basis.
- **What are your main areas of research interest?**  
In the Israeli IBD Society there are various areas of research focus and expertise, including epidemiology, mucosal immunology, clinical trials, drug mechanisms of action,

- optimisation of biologic therapy, genetics and paediatric IBD.
- **Does your centre or country have a common IBD database or bio bank?**  
This is being established currently.
- **What are your most prestigious/interesting past and ongoing projects?**  
Based on our fields of expertise, Israeli gastroenterologists have contributed to ECCO guidelines in several fields and have published important manuscripts in the fields of epidemiology, mucosal immunology, optimisation of drug (specifically biologic) therapy, diagnostics and paediatric IBD.
- **Which ECCO projects/activities is the group currently involved in?**  
Israeli gastroenterologists are involved in ECCO activities such as guidelines, workshops and SciCom activities.
- **What are your aims for the future?**  
To increase collaboration between Israeli

- centres; to encourage centre-specific research expertise; to increase participation in ECCO activities.
- **How do you see ECCO helping you to fulfil these aims?**  
Approaching National Representatives/ECCO functionaries in order to recruit speakers/participants in ECCO activities.
- **What do you use ECCO for? Network? Congress? How do you use the things/services that ECCO has to offer?**  
ECCO is important for its congress and activities such as guidelines, workshops and development of future directions.

**IRIS DOTAN, SELWYN ODES**  
ECCO National Representatives, Israel



## Questionnaire – SWEDEN

### • How did your national group start?

SOIBD started as a group of Swedish gastroenterologists and colorectal surgeons interested in IBD research from different university hospitals in Sweden. One of the aims was to stimulate national research in IBD in a large population. Initially membership was possible after proposal from members, but since 2009 it has been possible to apply for membership.

### • How is your group organised in terms of new members joining the group, meetings, election of president etc.?

In order to obtain membership, a written application must be sent with a letter of intent and a CV to the scientific secretary. The applicant must have produced a thesis and have an interest in active research in IBD. Membership also entails participation in a working group. At present there are four working groups: the microscopic colitis group, the therapy group, the surgery group and the group of pathophysiology and genetics. The president is proposed by an election committee.

### • When did your group join ECCO?

Sweden officially joined ECCO as a country member in 2004. The group joined in 2011. Some of the members joined ECCO earlier.

### • What are your main areas of research interest?

Pathophysiology, genetics, immunosuppressive therapy and surgery in IBD are, in addition to microscopic colitis, the main areas of research in SOIBD.

### • Does your centre or country have a common IBD database or bio bank?

SOIBD has understood the value of a national IBD register and has financially contributed to the development of SWIBREG (Swedish IBD Register). At present this register contains data for 18,000 IBD patients. SOIBD has also contributed patient material for The Swedish National Programme for IBD Genetics (SNP),



Members of SOIBD (Source: Leif Törkvist)

### • What are your most prestigious/interesting past and ongoing projects?

A number of published studies have their origin in SOIBD. During the last decade, 27 original papers have been published in which at least two SOIBD members from different universities have participated. The well-known rescue therapy study with infliximab by Gunnar Järnerot involved several members of SOIBD. Recently, a treatment study with budesonide in microscopic colitis was completed and a study with allopurinol and thiopurines is planned. The therapy group plans to start a therapy study in IBD in cooperation with the French research group, GETAID. The pathophysiology group is now starting an observational study in patients with new onset of IBD. Among other things, they aim to collect samples for genetic and immunological analyses in a longitudinal manner. SOIBD has, in cooperation with the Swedish Gastroenterology Association (SGF), developed national guidelines within IBD.

### • Which ECCO projects/activities is the group currently involved in?

Members of SOIBD have participated in the ECCO Workshops.

### • What are your aims for the future?

SOIBD plans to increase the national research in IBD. The main tool for this is the national database, SWIBREG, which is now implemented in IBD units in Sweden. We

also want to increase our international cooperation in IBD research by starting more projects together with other IBD research groups in Europe and other parts of the world.

### • How do you see ECCO helping you to fulfil these aims?

The ECCO organisation can contribute to the networking necessary for starting up international research projects. By organising scientific and educational workshops in Sweden, ECCO can help SOIBD to spread knowledge and enthusiasm in the IBD area.

### • What do you use ECCO for? Network? Congress? How do you use the things/services that ECCO has to offer?

Members of SOIBD have participated in the work with different Swedish guidelines in IBD. In their work they have used the ECCO Guidelines as a base. A majority of the members of SOIBD participate at the ECCO Congresses and some of them present their research at these meetings. The members of SOIBD use ECCO material, such as JCC and ECCO Guidelines, for their clinical and research updates. Gothenburg in the southwest of Sweden has applied to host an ECCO Congress in 2014 and 2015.

**HANS STRID, LEIF TÖRKVIST**  
ECCO National Representatives, Sweden

## ECCO Country Profiles

Dear ECCO Country Member,  
Dear ECCO National Representative,

The original idea of the founders of ECCO was the constitution of an organisation of the National IBD Study Groups within Europe. After an initial membership of five countries in 2001, most European countries joined ECCO in the following years. Since its foundation, ECCO has been continuously supported by its national counterparts and ECCO is therefore honoured to embrace 31 Country Members, each of which

is represented by two National Representatives – the driving force and ambassadors of ECCO.

In the upcoming issues of ECCO News we therefore want to **introduce our ECCO Country Members** (National IBD Study Groups) based on a predefined questionnaire which has been answered by their ECCO National Representatives. Please **get in touch with the ECCO Office (b.schmid@ecco-ibd.eu) for contribution in the upcoming issues.**

## ECCO Governing Board 2012



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**EpiCom**  
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Stephan Vavricka, Switzerland  
Sandro Ardizzone, Italy

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