

# ECCO NEWS 2007



EUROPEAN CROHN'S & COLITIS ORGANIZATION

2

2007 VOLUME 2

- IBDIS® – Harmonizing the documentation of IBD patients within ECCO
- The ECCO Consensus on Crohn's Disease
- Report from ECCO Congress in Innsbruck

The Quarterly Publication of ECCO  
European Crohn's & Colitis Organization

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## LETTER FROM THE PRESIDENT

### Dear Colleagues,

I am addressing you again after the second ECCO Congress held in Innsbruck from the 28th of February to the 1st of March 2007. As you know our first congress held in Amsterdam was designed to provide high standard, up-to-date information in the form of lectures and a life-endoscopy session – the congress was a real success. The Innsbruck congress was designed in a more traditional type of format, with the possibility of submitting original scientific work, whereas the program included high standard lectures and debates delivered by highly reputed basic scientists and clinicians. I very proudly can say that this second congress was a real success. More than 280 abstracts were submitted and peer reviewed. There were more than 829 professionals registered (European and non-European), 15 exhibiting booths and more than 100 industry members attending.

The program included nine lectures, with a special Opening Lecture by Professor Robert Modigliani, six debates, 10 oral papers, 20 posters and a summary of the recent ECCO Consensus on Ulcerative Colitis.

**The lecture hall was always full.** A remarkable comment from industry exhibitors was that the exhibition hall was usually empty when lectures, papers or posters were being delivered or presented. The exhibition was full only during coffee breaks and, of course, during the fantastic party in the evening of the second congress day. The comments and the results of the survey about contents and organisation of the congress were very favourable with high scores in most items. During the meeting the ten highest scored original papers presented by young investigators received a prize of 500 € each, and the Second ECCO Fellowship of 30.000 € was awarded to Dr Konstantinos Karmis.

**An important event** was the presentation of our new journal: the Journal of Crohn's and Colitis (JCC). ECCO has high expectations with this journal which should become, together with our congress, the big ECCO window where the scientific activity on IBD should find a high quality and quick way of publication. It is our journal and I ask for your support to raise and



**President**  
**MIQUEL GASSULL**  
Badalona, Spain

maintain its high quality. The congress' abstracts were published in the first issue of JCC Supplements. Please, visit the JCC website: [www.ecco-jcc.org](http://www.ecco-jcc.org)

**Prior to the congress**, the 5th Intensive Advanced Course on IBD for Junior Gastroenterologists took place, with about 50 young physicians attending from 25 member countries. As usual, the course was of intense work and, according to the satisfaction survey, it met the expectations of the attendants. At the same time, a meeting was held, organised and lead by specialist IBD Nurses. It was attended by 60 nurses interested in IBD and the common conclusion was that this activity has to be continued, not only as a meeting prior to the ECCO Congress, but as a continuous work during the year in order to design a training program applicable, if desired, to all ECCO member countries.

A high activity level of the Young ECCO members (YECCO) was also detected. This group showed their strength and enthusiasm, during its own meeting prior to the congress in which, potential translational research studies were discussed and proposed to ECCO Scientific and Educational Committees for their evaluation. They have our full support.

**Last but not least**, ECCO Governing Board also held meetings with the European Federation of Crohn's and Colitis Associations (EFCCA). ECCO is very conscious that our main objective is to improve the care of IBD patients and this objective will be better achieved working together with them. The seeds were planted for a continuous collaborative work and conversations are actually taking place between EFCCA and ECCO representatives which I am sure will fructify in important projects.

In summary, ECCO Governing Board is very satisfied by this experience, in which the high interest in this congress and in ECCO activities shown both in Europe, and also outside Europe (we had a group of specialists coming from South-America). ➡



## LETTER FROM THE PRESIDENT

We had also the impression that the translational approach implemented in all ECCO activities (scientific and educational) are well appreciated and valued by those professionals involved in research and those taking care of the patients with IBD.

I would like to show my deep recognition to: the Scientific and Educational Committees of ECCO for setting the scientific program and educational activities, to Dr Herbert Tilg and the Local Organising Committee for the formidable and

friendly organisation, and to Mrs. Ina Kähler and PCO Tyrol for the precise work done.

**If you think that ECCO** feels that it has accomplished its objectives, you are wrong. ECCO is in continuous evolution. In previous letters I have mentioned some of our projects; in the forthcoming letters I will go more in detail into them and the changes ECCO will experience in a very near future.

Special mention of gratitude has to be made to all ECCO Corporate Industry Mem-

bers for the continuous help to carry on with our scientific and educational activities. Also thanks, to all the industry exhibiting during our congress. Finally, to all of you, IBD patients, specialist nurses, basic scientists, and IBD doctors for supporting ECCO.

The preliminary program of IBD 2008, the 3rd ECCO Congress to be held in Lyon (France), is already displayed at the ECCO website ([www.ecco-ibd.org](http://www.ecco-ibd.org))

MIQUEL GASSULL, President of ECCO



## OBITUARY: ANTONI OBRADOR

# Obituary: Antoni Obrador (1951–2006)

**It is my sad and difficult task to write about the death of Antoni Obrador M.D.**

**D**r Obrador was head of the Department of Gastroenterology of the Hospital "Son Dureta", a teaching hospital in Palma de Mallorca, where since many years he developed an intense and important activity both as a physician and as a researcher.

In the early eighties, after some years of observing a raising number of colon cancer diagnosed and operated in Mallorca, he designed and established the first proper colon cancer registry in the island (and probably in Spain). Later, Dr Obrador published various papers on this subject and soon became well known in the field and collaborated with various European working groups in this area, such as the European Colon Cancer Prevention and others. He was also one of the first gastroenterologists who became interested in IBD in Spain and was a founding member of the Spanish Group for the Study of Crohn's Disease and Ulcerative Colitis (GETECCU). He developed a great activity within this working group as secretary, vice-president and finally president – a position he held when he unfortunately died.

Antoni has been a very close friend of mine for almost 30 years; this is why it is difficult for me to write about him. It is difficult to find the proper words to express ones feelings, even in our own language. Antoni was a real human being, if you allow me. He had very firm ethical convictions, which drove all his actions, while

at the same time had a very open mind. He always managed to find a door to be open in every difficult situation, without renouncing at his convictions. He was also very respectful with everyone dealing with him. He may look, to those not knowing him well, as being shy or a grey type of character. He was neither of those. Antoni had strong convictions; he did not show up much if it was not necessary, but during his life he gained the respect and sympathy of all of those knowing and working with him, because of his straight-forward, but always kind attitude.

Dr Obrador, developed an intense activity in GETECCU. He was one of the organisers and program designers, together with Jaquín Hinojosa, Fernando Gomollón and myself of the yearly activities of the National Group. Among those, the twice a year Intensive IBD Junior Course (16 courses already), the first IBD educational journal "EII al dia" (IBD up-date) published quarterly and the GETECCU Newsletter.

Antoni, was also one of the founders of ECCO. He was attending on my behalf and as Vice-president of GETECCU, the founding meeting of ECCO in Vienna. He represented GETECCU in the ECCO council until his death the 28<sup>th</sup> of November 2006.

In addition of being an excellent and judicious physician and researcher, he was also a man with a vast culture. An insatiable reader of universal literature, he was also an expert on local traditions and on local literature. He was appointed member of



Dr Antoni Obrador

the Royal Academy of Medicine of the Balearic Islands and the lecture he gave when taking over his seat was on "*The medical diagnostics and remedies in the traditional fair-tales of Mallorca*" delivered and written in his own language.

Those who have had the privilege of knowing and working with Antoni Obrador, are missing Antoni very much. This is especially so with me because our long friendship. I visited him in the hospital in Mallorca two weeks before he died. He showed, as always, very high spirits and a very positive attitude with his disease; he never showed to anyone that was going to give up and we even talked about future projects for GETECCU in the following years.

Antoni Obrador has left a profound impression to all of us because of his personality, integrity, wise way of thinking, well doing and refined sense of humour. We will always remember him. Rest in peace.

MIQUEL A. GASSULL



# IBDIS® – Harmonizing the documentation of IBD patients within ECCO

## History

In 1999, Walter Reinisch from the General Hospital in Vienna and Nikolaus Pedarnig, founder and owner of UNIDATA GEODESIGN, started to outline the concept of a standardized documentation of IBD patients. A close co operation between science and technology was established to realize a project, which aims to result in the development of a validated and reliable catalogue of parameters relevant for scientific approaches and daily practise in inflammatory bowel diseases. The creation of a European IBD documentation standard in mind, the parameter catalogue was subjected to an interobserver assessment study and succeedingly implemented by UNIDATA GEODESIGN into a web based software. By using the worldwide web as the communication forum, code-controlled access is granted and broad availability to the community enabled.



The UNIDATA GEODESIGN website: [www.ibdis.net](http://www.ibdis.net)

## Partnership ECCO and IBDIS®

During the ECCO-Congress 2007 in Innsbruck the governing board of ECCO and UNIDATA GEODESIGN signed a contract about a close cooperation in future projects. IBDIS® is now a ready to use service free of charge for all ECCO members. The potential applicability of IBDIS is manifold, reaching from an electronic patient record form for clinical routine to a scientific tool for standardized patient documentation and phenotyping within the scope of clinical studies or registries.

## Major goals and advantages

Using IBDIS® and its documentation tool adds the following advantages to the IBD community and all ECCO members:

- Ready to use after a long process of planning, developing, improving and testing the software including a risk analysis with identification, assessment, treatment and documentation of risks.
- Broad availability using the Internet and latest online techniques.
- IBDIS® is based on a harmonized, standardized and validated catalogue of IBD parameters.

- Continuous enhancement by implementation of technical and scientific advances, as well as repeated validation processes, now also with professional support by ECCO.
- IBDIS enables the comparison of patient populations in scientific studies based on the same documentation standard.
- IBDIS® offers a wide range of facilities to use it as an easy to adapt tool for special user requirements including registries, online surveys or EU projects.
- Several partners within the pharmaceutical industry already trust in IBDIS and the technique behind the system for their own eCRF's.
- Using a web based eCRF is a strategic move and a statement to be aware of the requirements and challenges of regulatory authorities.

## How to use IBDIS®

Reliably and validly documented information on the patient is in the centre of interest of the IBDIS software application (Fig. 1).



Fig. 1. IBDIS® modules.

According to the wide range of purposes of using the IBDIS® software, UNIDATA GEODESIGN has defined 3 types of licenses:

**Category I:** Anonymized patient documentation with complete use of the application modules: Demographics, diagnosis, complications, risk factors, pregnancy, surgical and medical therapy. This licence uses the UNIDATA GEODESIGN server archi-

ture and is free of charge for all ECCO members. Using this licence requires only online registration via the UNIDATA GEODESIGN website [www.ibdis.net](http://www.ibdis.net)

**Category II:** Personalized patient documentation with full integration into the clinical routine and complete use of the application modules. Due to data security and privacy protection requirements of public authorities and the guidelines of the European Commission, UNIDATA GEODESIGN offers this category II facility. This license requires integration into the clinical centres server architecture by using a dedicated and supported IBDIS.NET server. This license brings an overall IBDIS® documentation of IBD patients by small costs. All patient data is stored at the clinical centre. The data can be anonymized for multi-centre or multinational analysis.

**Category III:** This IBDIS® license is used for user specified eCRF's for clinical trials from phase I to IV or for registries or named patient programs. UNIDATA's experience in consulting the pharmaceutical industry led to a number of national and Europeanwide registries on treatment in IBD as well as for other indications. Each eCRF is equipped with an integrated service tool for monitoring the data. This

leads to reduced monitoring costs during the process of a study and improves the quality of data. UNIDATA GEODESIGN follows the guidelines for developing validated software applications (Fig. 2).



**Fig. 2.** Life cycle of planning and developing validated software according to national and international guidelines from defining user requirement specifications until roll out and maintenance periods.

**eCRF features at a glance**

- Easy to use data capturing.
- Standardized documentation.
- Integrated plausibility checks.
- Integrated query management and monitoring tools.
- Optimized roles and authorizations
- Worldwide availability.
- Compliance with the requirements of the FDA (21 CFR Part 11 Electronic Records and Electronic Signatures) and GAMP.

**Conclusion**

**Quality of data**

IBDIS® aims to improve the quality of data on IBD patients. The catalogue consists of more than 180 parameters that have passed an interobserver agreement analysis to evaluate scales, ranges and definitions. IBDIS® uses integrated and automated plausibility checks, a permanent Audit Trail, record retention and archiving tools to maintain the best quality of data. Every application of IBDIS® is equipped with an online support and information system (IBDIS® Knowledge-base).

**Partnership**

ECCO and UNIDATA GEODESIGN committed themselves to cooperate in the field of standardized patient documentation and to improve the quality of care of IBD patients. The outstanding experience of all ECCO members and their leadership in the knowledge about IBD and the technical Know-how provided by UNIDATA GEODESIGN are excellent bases to achieve these objectives.

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## NEW!!! ECCO Fellowships and now also ECCO grants!!!

The **ECCO Fellowships** which have been established to encourage young physicians in their career and to promote innovative scientific research in IBD in Europe, have entered their second year.

During the ECCO congress in Innsbruck; Dr. Kostas Karmiris from Greece, was awarded the Fellowship for the project entitled "Pharmacokinetic study on clinical outcome and immunogenicity of anti-TNFα agents (infliximab, adalimumab and certolizumab pegol) effective in inflammatory bowel diseases".

The project of Dr Karmiris will be carried out at the University Hospital of Leuven, Belgium.

ECCO continues to promote its fellowships and announced to increase the

number to 2 each year. Fellowships are created for young individuals <40 years, who submit an original research project, which they wish to undertake abroad in a European hosting laboratory and/or department who has accepted to host and guide the fellow for the duration of the fellowship (one year) and who is responsible together with the fellow for the successful completion of the project.

Fellowships are awarded a total amount of 30,000 Euros.

Besides the Fellowships, ECCO is now very pleased to announce **ECCO grants**, to support good and innovative scientific, translational or clinical research in Europe. The guidelines of ECCO grants are very similar to those of the Fellowships,

with the exception that the research is typically undertaken in the own institution of the applicant.

ECCO grants are awarded 15,000 Euros each and will also be given during ECCO's annual congress. The deadline for submission of the Fellowships and the grants is December 1<sup>st</sup>, 2007.

Full instructions and application forms for ECCO Fellowships and grants can be found on [www.ecco-ibd.org](http://www.ecco-ibd.org) – the ECCO homepage.

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# Professor Colombel: We need to learn from the Rheumatologists!

**Professor Jean-Frédéric Colombel was invited to the Swedish Society of Gastroenterologists Annual Congress in Uppsala, Sweden.**

**T**he headline of Professor Colombel's talk was *Management of Crohn's disease, today and tomorrow*.

One of the things he emphasized in his speech, was that Gastroenterologists in the future have to be more aware of diseases that are not normally in their field.

He also thought that Gastroenterologists had a lot to learn from Rheumatologists.

## **The Pyramid**

In his lecture, Professor Colombel pointed out that it is important to take the patients perspective. He listed the most important concerns of patients with IBD.

– Patients want to avoid surgery, having an ostomy bag, hospitalization, side effects of drugs and an uncertain evolution of the disease, he said and added:

– But you must tell the patient it's a progressive disease.

He continued to show the traditional way of treating these patients by presenting the options in the form of a pyramid.

The base of this pyramid shows mild disease, and here treatment with Aminosalicylates and Antibiotics is recommended. The middle represents moderate disease and the options for treatment are Immunomodulators and Corticosteroids.

At the top of the pyramid – that indicates severe disease– surgery has been the only option until 1995, but since then another has been added: Anti-TNFs.

## **Step up in a proper way**

This pyramid represents the traditional “step-up” therapy, and it has been recently suggested to invert this – to start at the top with Anti-TNF for patients with mild disease and then gradually, as the patient is getting better, step down the treatment.



Jean-Frédéric Colombel

“ Today the chance of the European population of getting IBD is 1%, that is to say one person out of one hundred is going to be ill!

This procedure has been debated for some time, and Professor Colombel himself asked rhetorically if we are ready to do so.

– Probably not, he answered his own question.

– We have to learn more about side effects and the risk of infection.

But he underlined that we can not keep patients on steroids for several years. They also have serious side effects. Among these

are osteoporosis/osteonecrosis, higher risk of infections, oedema/cushing syndrome and cataracts/glaucoma.

Therefore he said that the treatment should step-up “in a proper way”.

## **The work has started**

Here Professor Colombel referred to Rheumatologists.

– They monitor a validated surrogate of disease progression – and that is what we need in Gastroenterology as well, he said.

– A Rheumatologist wants to avoid bone destruction, because once that has happened it's too late. Therefore they have created a score to monitor the disease. It's called the SHARP Score. By using this, they are able to predict *when* to step up the treatment in order to stop bone destruction.

– We need a score like that for IBD, of course in order to avoid bowel damage instead. We are late, but this work has started.

He quoted the world famous Professor Hanauer, who in 2006 had said that appropriate patient selection for more aggressive treatments becomes essential.

Another quote from Professor Hanauer – about how to determine high risk patients – caused a lot of laughter in the lecture hall.

– I would have to say as the U.S. Supreme Court did when defining pornography: It's hard to define – but I know it when I see it!

## **Epidemic**

In his lecture, Professor Colombel described how the three new Anti-TNF@ biological agents – Infliximab, Certolizumab and Adalimumab – was constructed.

A week before his lecture, Adalimumab was approved in Europe.

– And Certolizumab is expected to be, he added.

He also referred to a recent study that showed that if one of these Anti-TNF didn't help a patient, another might very well do so. ➡



– So if one doesn't work – try another!  
 Professor Colombel thinks it's clear that we will use these "biologicals" increasingly in the coming years.

– We need more aggressive treatments, and we need a combination of treatments.

Another important fact is that IBD in Europe is becoming epidemic.

– Today the chance of the European population of getting IBD is 1%, that is to say one person out of one hundred is going to be ill!

**Watch out for other diseases**

So therefore it is important to try to identify these patients as early as possible.



– Keep alert – look for the disease, is Professor Colombel's advice to his European colleagues.

Other advice is to be aware of side effects. The new biological treatments lower the immune response, and these patients can contract TB among other diseases.

– So Gastroenterologists have to be aware, and look for diseases that are not normally in their field.

– The first thing I do with a CD-patient is to give him my card with all my numbers on. Then the patient can call me as soon as something happens, says Professor Colombel.

**PER LUNDBLAD**  
 Senior Writer

# Notice of forthcoming elections

Dear ECCO National Representative,  
 Dear Colleague in IBD!

Notice is hereby given, that the following position on the Scientific Committee of ECCO is open for election:

- *ECCO Scientific Committee member*

Candidates may be self nominated or proposed by an ECCO National Representative.

**Deadline for receipt of all nominations is July 1, 2007.**

A candidate for an office of ECCO must be an established specialist in the area of IBD.

The candidate should submit a CV and a letter of intent, explaining his/her suitability for the office in question. The term for the Committee officer starts on March 1, 2008

and ends on March 1, 2010. The nominee must agree to his/her nomination.

Election forms can be obtained from the ECCO Executive Secretariat upon request at [ecco@vereint.com](mailto:ecco@vereint.com). Please send all forms to the ECCO Executive Secretariat.

With best regards,

**DANIEL HOMMES, M.D.**  
 Chair, ECCO Scientific Committee



## ECCO'S website

Find out more about ECCO on the web. Please note the address – **[www.ecco-ibd.org](http://www.ecco-ibd.org)**

Here you can find useful information about many details concerning ECCO. It's easy to navigate via menus which can be found to the left and at the top of the page. E-mail links to the Governing Board are provided.

The website also contains many other links, both internal and external. Documentation for ECCO projects can be downloaded and links to partner organizations can also be found here. On the website there are also links to forthcoming and past events, and links leading to information on trials about IBD in Europe. The history of the organization itself can also be downloaded.

In order to keep yourself updated – don't forget to add **[www.ecco-ibd.org](http://www.ecco-ibd.org)** to your Favourites!

**ECCO GOVERNING BOARD 2007**



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## JOIN ECCO AS AN INDIVIDUAL MEMBER IN 2008!

Dear Colleagues!

ECCO has decided to change its structure to **individual membership**. If you are interested, please fill out the form below and mail it to the **ECCO Secretariat at [ecco@vereint.com](mailto:ecco@vereint.com)**, fax it to **+43 (1) 212 74 71 – 49**, or **send it by post to ECCO Executive Secretariat, Hollandstrasse 14 / Mezzanine, A-1020 Vienna**.

Information on the complete membership package will then be sent to you later in 2007. As a thank-you for your interest, you will receive **a free subscription to JCC – The Journal of Crohn's and Colitis** for 2007.

### Membership benefits include:

- ✱ **Congress: reduced registration fee**
- ✱ **ECCO IBD Nurses course: reduced registration fee**
- ✱ **A free subscription to JCC – The Journal of Crohn's and Colitis (4 issues/year)**
- ✱ **ECCO News**
- ✱ **Ongoing information on ECCO activities**
- ✱ **[www.ecco-ibd.eu](http://www.ecco-ibd.eu) with membership log-in**
- ✱ **Possibility to apply for IBD courses, grants and scholarships**



I AM INTERESTED TO LEARN MORE ABOUT ECCO'S INDIVIDUAL MEMBERSHIP:

Title: ..... First Name: .....

Surname: .....

Degree/University: ..... Year:.....

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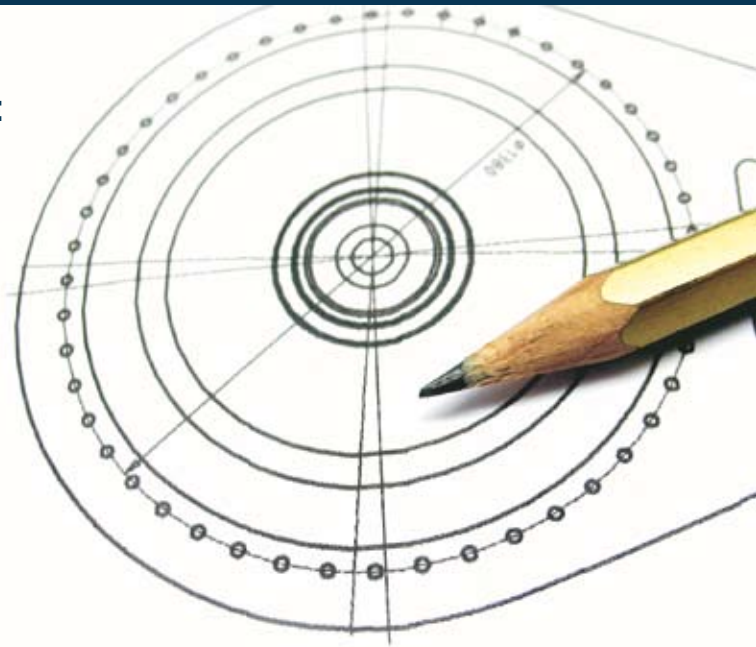
Date: ..... Signature: .....



# What's it all about?

## SIMON TRAVIS

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**REPRINT** This consensus article was first published in ECCO News 1/2006

**Therapeutic guidelines, be they national or international serve two purposes: they distil the essence of good practice and have the potential to modify care. The delivery of neither purpose can be taken for granted. In the first case, distillation of good practice must be based on a formal process for reviewing the evidence base and making graded recommendations. Otherwise guidelines are wont to express the therapeutic opinions of self-appointed experts. This is the GOBSAT approach (Good Old Boys Sitting Around a Table), which is still prevalent in areas where it is customary to defer to senior opinion rather than question every assumption. The publication of guidelines is also no guarantee that practice will change. Guidelines serve no purpose if they sit on the office shelf. There need to be mechanisms by which change is delivered, from raising awareness of the content down to the level of the clinic where decisions are made, and up from the level of patients who are increasingly well informed.**

**T**he limits of Evidence-Based Medicine are, however, immediately apparent when guidelines are written. Guidelines are demanded when there is a lack of evidence or conflicting evidence, so sceptics observe that 'evidence-based guidelines' are a contradiction in terms. Evidence is conclusive in some areas, but remarkably thin in others. ECCO is a forum for specialists in inflammatory bowel disease from 23 European countries. The ECCO Consensus is the most robust process anywhere in the world for developing clinical guidelines on the management of inflammatory bowel disease, and Europe is leading the way. It sets out to quantify and articulate opinion in addition to a systematic review of published evidence.

Clinicians have to advise patients on the basis of information available today. Despite a multiplicity of randomised trials there will always be questions that can only be answered by the exercise of judgement and opinion. This leads to differences in practice between clinicians, which are brought into sharp relief by differences in management between countries. The Consensus endeavours to address these differences. The aim is to promote a European perspective on the management of inflammatory bowel disease and its dilemmas. This matters not only for daily practice, but also for clinical trials. An increasing number of therapeutic trials are based in Europe, especially in central or eastern European countries

where practice guidelines have yet to be published.

## Consensus Process

The strategy to reach the Consensus involved five steps:

- 1.** Questions on dilemmas in the diagnosis and treatment of Crohn's disease or ulcerative colitis were written by working parties and circulated to 60 specialists in IBD across Europe. The specialists, all recognised authorities in the field, were asked to answer the questions based on their experience, as well as evidence from the literature (Delphi procedure).
- 2.** A systematic literature search of individual topics was performed and the evidence level (EL) graded according to the Oxford Centre for Evidence Based Medicine [[http://www.cebm.net/levels\\_of\\_evidence.asp](http://www.cebm.net/levels_of_evidence.asp)].
- 3.** Provisional guideline statements were written by the working parties on each of 14 topics.
- 4.** Participants then met to agree the final version of each guideline statement. This was achieved by projecting and revising the statements on screen until a consensus was reached. Consensus was defined as agreement by >80% of participants. Each recommendation was graded (RG) according to the level of evidence.
- 5.** The supporting text of the document was then written by the working parties. ➡

### Outcome

The outcome for Crohn's disease was a 38 000 word and 738-reference review, with 124 ECCO statements grouped into three sections (*Gut* 2006; 55 Suppl I:i1-158). This was peer-reviewed by US experts before publication. The first section concerns aims and methods, as well as diagnosis, pathology, and classification of Crohn's disease. The second section on Current Management includes treatment of active disease, maintenance of medically-induced remission and surgery of Crohn's disease. The third section on Special Situations in Crohn's disease includes post-operative recurrence, fistulating disease, paediatrics, pregnancy, psychosomatics, extraintestinal manifestations and alternative therapy. The Consensus on the management of ulcerative colitis is in progress.

### ECCO statements and qualifying text

#### Active Crohn's disease

For each statement there is a qualifying text, since the Consensus inevitably contains contentious comments. An example is the lack of efficacy of mesalazine for Crohn's disease. The ECCO statement declares that 'for mildly active localised ileocaecal Crohn's disease, budesonide 9mg daily is the preferred treatment [EL2a, RG B]. The benefit of mesalazine is limited [EL1a, RG B]. Antibiotics cannot be recommended [EL1b, RG A]. No treatment is an option for some patients with mild symptoms [EL5, RG D]'. This four sentence statement is then qualified (references are of course given in the paper). Budesonide 9 mg daily is favoured because it is superior to both placebo (OR 2.85, 95% CI 1.67-4.87) and mesalazine 4g/day (OR 2.8, 95% CI 1.50-5.20) and achieves remission in 51-60% over 8-10 weeks. Budesonide is preferred to prednisolone for mildly active CD because it is associated with fewer side-effects, although a Cochrane systematic review has shown budesonide to be somewhat less effective (pooled OR for the 5 trials = 0.69, 95% CI 0.51-0.95). The text goes on to explain that mesalazine is not recommended for mildly active ileal CD, because a meta-analysis has shown that it only has a limited effect compared to placebo. In this meta-analysis there was a significant reduction in the CDAI in patients with active ileocaecal CD re-

| Topic                          | Working Party (Chair underlined)                   |
|--------------------------------|--|
| Definitions and methods        | <u>Stange</u> , Lémann, Forbes, Travis             |
| Classification                 | <u>Vermeire</u> , Hommes, Schreiber                |
| Diagnosis                      | <u>Reinisch</u> , Herfarth, Mantzaris              |
| Pathology                      | <u>Geboes</u> , Flejou, Stolte, Villanacci, Warren |
| Active disease                 | <u>Travis</u> , Stange, Chowers, Marteau           |
| Maintenance                    | <u>Lémann</u> , Colombel, D'Haens, Ghosh, Kruis    |
| Surveillance                   | <u>Michetti</u> , Kiesslich, Novelli               |
| Surgery                        | <u>Oresland</u> , Mortensen, Bemelman, Gassull     |
| Pouchitis                      | <u>Pallone</u> , Gionchetti, Biancone, Warren      |
| Children & adolescents         | <u>Escher</u> , Kolacek                            |
| Pregnancy                      | <u>Munkholm</u> , Vibewer, Lebech, Lukas           |
| Psychosomatics                 | <u>Moser</u> , Jantschek, Vucelic                  |
| Extraintestinal manifestations | <u>Forbes</u> , Panes, Neurath                     |
| Complementary therapies        | <u>Hoffmann</u> , Dignass, Mitchell                |

**Table 1:** Working Parties for UC Consensus.

| Name      | Country     | Name         | Country     | Name             | Country     |           |
|-----------|-------------|--------------|-------------|------------------|-------------|-----------|
| Beglinger | Switzerland | Lakatos      | Hungary     | Tilg             | Austria     |           |
| Buhr      | Germany     | Lofberg      | Sweden      | Tsianos          | Greece      |           |
| Campieri  | Italy       | Moum         | Norway      | Tysk             | Sweden      |           |
| Caprilli  | Italy       | O'Morain     | Ireland     | Van der woude    | Netherlands |           |
| Cortot    | France      | Panis        | France      | Vecchi           | Italy       |           |
| Cottone   | Italy       | Penninckx    | Belgium     | Zeitz            | Germany     |           |
| De Vos    | Belgium     | Pokrotnieks  | Latvia      | <b>Observers</b> |             |           |
| Eliakim   | Israel      | Prantera     | Italy       |                  | Foch        | Singapore |
| Freitas   | Portugal    | Rhodes       | UK          |                  | Yap         | Australia |
| Gregus    | Slovakia    | Schoelmerich | Germany     |                  |             |           |
| Hawkey    | UK          | Shanahan     | Ireland     |                  |             |           |
| Jewell    | UK          | Seibold      | Switzerland |                  |             |           |
| Jojic     | Serbia      | Soderholm    | Sweden      |                  |             |           |
| Kupsinkas | Lithuania   |              |             |                  |             |           |

**Table 2:** Other participants and Voting members in the UC Consensus.

ceiving mesalazine 4g/day, but this was just 18 points compared to placebo (-63 vs -45, p=0.04) in 615 patients. It must of course be remembered that treatment with placebo is not the same as no treatment at all.

#### Infliximab and surgery

Another contentious area was the timing of infliximab therapy. Concerning this, the statement declares that 'severely ac-

tive localized ileocaecal Crohn's disease should initially be treated with systemic corticosteroids [EL1a, RG A]. For those who have relapsed, azathioprine/mercaptopurine should be added [EL1a, RG B], (or, if intolerant, methotrexate should be considered [EL1a, RG B]). Infliximab should be considered in addition for steroid- or immunomodulator-refractory disease or intolerance [EL1b, RG A], although surgical options should also be



considered and discussed.' The qualifying text explains that this does not mean that surgery takes precedence over infliximab. Both the indication and timing are joint decisions between patient, physician and surgeon. Infliximab has emerged as a conservative option for cases with severe inflammatory activity and it is in these that primary surgery will often be inappropriate. Surgical options should, however, be considered and discussed with the patient as part of an overall management strategy. The stage at which infliximab is introduced may change if it can be established whether early therapy alters the pattern of disease. The threshold for surgery for localised ileocaecal disease is lower than for disease elsewhere, and some experts advocate surgery in preference to infliximab for disease in this location. All medical treatment has to be placed in the context of a high likelihood of needing surgery. In 592 patients followed over 13 years, 91% of those with ileocolic disease, 72% with pancolonic, 65% with isolated small bowel, and 29% with segmental colonic disease came to surgery. Therefore, surgery should always be considered as an option. Both the indication and timing are important interdisciplinary issues. With the advent of infliximab a new conservative option has emerged for cases with severe inflammatory activity and it is in these that primary surgery will often be inappropriate. Thus, neither conservative nor surgical options should be given precedence over the other, but in these difficult cases the best approach should be tailored to the individual. The evidence (up to December 2005) for the role of infliximab and other biologic therapy is detailed in the consensus document.

*Psychosomatics and alternative therapy*

An unusual feature of the Consensus is that it addresses topics that are often considered on the margins of mainstream medicine. These include psychosomatics and alternative therapy. For example, the first ECCO statement on psychosomatics declares that 'psychological disturbances seem to be a consequence of the illness rather than the cause or specific to Crohn's disease. The degree of psychological distress correlates with disease severity, predicts health-related quality of life and influences the course of disease [EL1b, 2b

and 3b, RG B]'. The qualifying text summarises the evidence (and lack of it) as well as identifying areas for future study. With regard to alternative therapy, a robust approach is taken. Several factors can lead both doctors and patients to think that an alternative therapy has worked, when in fact it has not. This is as true for new treatments in scientific medicine as it is for fringe practices in "complementary or alternative medicine" (CAM). For inflammatory bowel diseases, confounding factors include:

- 1.** the natural history runs a cyclical course, so alternative therapies will have repeated opportunities to coincide with periods of remission that would have happened anyway.
- 2.** placebo does work: through suggestion, belief, expectancy, cognitive reinterpretation, or diversion of attention, patients given biologically useless treatments often experience measurable relief. In recent IBD trials, placebo rates as high as 50% have been reported.
- 3.** if improvement occurs after IBD patients have had both "alternative" and science-based treatment, the alternative strategy sometimes gets a disproportionate share of the credit from patients, IBD groups, or organizations with vested interests.

**UC Consensus**

Following the successful completion of the ECCO Consensus on the management of Crohn's disease, a similar Consensus on the management of ulcerative colitis is taking place. Several lessons from the Crohn's Consensus have been taken on board: these include the need for a common process of systematic literature review through agreed key words; smaller working parties; and an open process to recognise the interests of industry over matters of factual accuracy.

The systematic literature review and questionnaire process has been completed and voting on statements among 61 participants, with observers from the Asia-Pacific region, takes place before UEGW in Berlin (20–21 October 2006). With regards to the interests of ind us-

try, there is clearly shared concern over matters of factual accuracy. The ECCO Statements are 'off-limits' and industry has no involvement in the working parties or Consensus, even as 'non-voting observers'. The supporting text, omitting the ECCO Statements, will be circulated solely for comment on factual accuracy to both ECCO Corporate Sponsors and non-Corporate members agreed by the President-elect, Steering Group and Scientific Committee before being submitted for peer review.

**Conclusions**

The Consensus on both Crohn's disease and ulcerative colitis represent real achievement by ECCO. The term Consensus represents a formal process, which is devalued if misused. It is difficult to believe that the process could have happened elsewhere and it has set an international standard for guidelines on the management of inflammatory bowel disease.

*Acknowledgements*

The Consensus has been driven by Eduard Stange (Stuttgart) and Simon Travis (Oxford), joined for the UC Consensus by Marc Lémann (Paris) and Alastair Forbes (London) in the guidelines steering group that is part of the Education committee of ECCO. Lynn and Sophie Lane have provided administrative support and helped collate results of the questionnaires. It could not have happened without the hard work and contribution of colleagues across Europe.



**SIMON TRAVIS**

# Inflammatory Bowel Diseases 2007

## – ECCO Congress in Innsbruck

**Innsbruck in western Austria is the Capital of the federal state of Tyrol. It's beautifully situated in a valley surrounded by the mighty Alps. It's one of the few places in the world where the Olympic games have been held twice. It was also the city where the 2<sup>nd</sup> ECCO Congress took place during the first three days of March 2007.**

In his statement during the opening ceremony, ECCO's President Miquel Gassull, greeted everyone that had come to the Congress.

– I am sure this meeting will be a successful one, he added.

### Big interest

He was right in his assumption.

A total of almost 1 000 delegates, including members of the pharmaceutical industry, turned up in Innsbruck for the Congress. This was an unexpectedly high number, according to Dr Herbert Tilg who was the Chairman of the Local Organising Committee.

– We did not expect more than 500–600, so we were very surprised, he says.

The facilities had no problem coping with it, though. The Congress Centre in Innsbruck is large and has outstanding technical facilities, which was one of the reasons that Innsbruck was chosen in the first place.

Another reason was the warm welcome given to the proposal by the Local Organising Committee itself.

### Nurses for the first time

The day before the Congress the 5<sup>th</sup> IBD Intensive Advanced Course for Junior Gastroenterologists started. At the same time the first ever ECCO Nurses Meeting was held. They both finished in the morning the next day.

Then the Congress itself started with the first in a series of four Satellite Symposiums.

Anders Nilsson, who held the chair, opened the Symposium with a short pres-



entation of Otsuka and then introduced Toshifumi Hibi, Tokyo, who talked about *IBD treatment in Japan*.

Salvador Peña, Amsterdam, who presented a lecture about *Immunomodulation in IBD*, followed.

### Introducing JCC

Then the official opening took place. President Gassull told the background story of ECCO and then presented what's new for 2007.

Among this he pointed out that ECCO had now opened up for individual membership while keeping the national representative council.

At the Congress applications for individual membership could be obtained from the ECCO booth in the Exhibition area, and every day a great number of these were collected.

Dr Gassull also introduced the Journal of Crohn's and Colitis – JCC. This has been launched by ECCO in an endeavour to convey relevant clinical, basic and translational research on IBD. It will be published every three months, and this first issue contained all the abstracts presented during the Innsbruck Congress.

He also pointed out that the Organisation is establishing a nursing IBD network and presented the ECCO Newsletter.

– ECCO News is a way of spreading news, and we expect your input so we can improve all the time, Dr Gassull said.

### From lobotomy to Infiximab

Clemens Sorg, Rector of the University of Innsbruck, took over and gave some facts about the University. He thanked Dr Tilg for planting the idea of having the conference here.

– I'm amazed by the amount of delegates you persuaded to come, he said.

Then the first scientific session started. Jean-Frédéric Colombel, France, and Paul Fortun, UK held the chair. They introduced Robert Modigliani, France, who held the ECCO Honorary Lecture – *IBD therapy from cerebral lobotomy to biological drugs*.

It turned out to be a very interesting historical survey of IBD therapy. As the title of the lecture hinted, Dr Modigliani revealed that lobotomy was once used to treat the illness.

– There was no regression, but the patient didn't care, he stated. ➡









Robert Modigliani



David Binion



Dermot McGovern



Stephen Targan



Fergus Shanahan

Adalimumab was given to this patient, she got better and also became pregnant. The audience then voted on the further treatment options. 15% voted for no change in therapy, 10% voted for stopping azathioprine and 10% wanted to stop adalimumab. No one voted for the option of stopping both drugs.

Obviously a lot of delegates did not vote at all.

– The audience does not believe in an immuno-suppressing effect of pregnancy, D’Haens concluded, and then turned to Colombel and asked for the Professor’s view on this.

– Findings do not suggest an increased risk for adversary pregnancy outcomes with exposure to adalimumab early in pregnancy, was his answer.

– But firm conclusions await accumulation of sufficient sample size, Colombel added.

Then the next case was presented, this time by Walter Reinisch, Austria.

The formula of showing different alternatives to the audience and then asking them to vote on different questions was repeated.

#### Identify environmental triggers

After this symposium, Dr Reinisch had to hurry to the another lecture hall as he held the chair for the next session. His co-chairman was Kostas Katsanos from Greece.

The first speaker was Stephen Targan, USA. His lecture had a question as a headline – *Who gets inflammatory disease?*

– The answer to that is simple: I don’t know, he confessed at the beginning of his speech.

He took diabetes as a comparison. There is a genetic disposition and an environmental trigger. Perhaps also a viral infection?

– The problem is that some develop subclinical disease in two months – some in 20 years, he said.

This is a pattern that is repeated in IBD. We know there exists a genetic disposition and the environmental triggers *could be* antibiotics, NSAIDS, infections and smoking to name a few, Targan continued.

– There are a lot of families that have the genes for developing IBD, but since they have not contracted the environmental factors they have not developed the disease.

– Now the aim is to find the genes involved, then we can trace backwards and try to identify different factors that are crucial for developing the disease – like we have in diabetes.

– Since the IBD-genome now is known, I think that time for achieving this is not ten years away – I’d say it’s more likely only five, Dr Targan summarized.

#### Searching for markers

Next speaker asked the same question, but was a little bit more specific. Dermot McGovern from UK wondered *Who will get severe colitis?*

Why identify, he wondered.

– It’s because we need that information when we discuss medical strategy, was Dr McGovern’s answer to his own question.

He pointed out that there is a mortality risk if we don’t identify “at risk” patients.

To predict colectomy there are different markers – radiological and clinical. There is also a scoring system:

– If on day three of intensive treatment the patient has a stool frequency higher

than eight a day, the probability of colectomy is 85%,

Clinical predictors of poor response are available. Careful clinical assessment and early surgery reduces the mortality rate to less than 1%.

– In the future we hope for a combination of clinical, biochemical, serological and genetic markers, Dr McGovern concluded.

#### Predictions

Yehuda Chowers, Israel, lectured on *Prediction of therapy response and side effects.*

Genetic factors determine drug efficiency and occurrence of side effects, and these factors can be used to predict therapeutic outcome, he stated.

– The metabolic pathway of Azathioprine is a good example, Dr Chowers continued.

Future trends for pharmacological development are to use well-defined patient populations for:

- Candidate gene approach
- High throughput screening
- Relevant functional studies

– The functional studies are really needed – we might be in for some surprises, he said.

Another prediction came from Axel Dignass, Germany – *Predictions of new targets for therapy.*

Professor Dignass talked about potential therapeutic modalities for the treatment of IBD. He thought of these as promising and that they will enlarge the therapeutic weaponry/arsenal for IBD.

– IBD therapy may require individually tailored therapies. Predictive markers to

tailor therapeutic strategies are mandatory.

– The role of cytokines and their modulation in IBD is still evolving. IBD is not one disease that will have one therapeutic option, was his conclusion.

#### Fellowship Award and Junior Club

One of the purposes of ECCO is to foster and encourage young gastroenterologists. Therefore Daan Hommes, The Netherlands, introduced the ECCO Fellowship Award.

This is a substantial prize: The sum is 30,000 Euro. For 2006 this Award was given to Fabian Schnitzler and his colleagues, and they presented their study *Long-term outcome of treatment with Infliximab in 440 Crohn's disease patients: Results from a single centre cohort*.

At the Congress Dr Schnitzler presented the study. His conclusion was that Infliximab is a very efficient drug therapy.

For 2007 Karminis Konstantinos received the Award. The aims of the study were presented in Innsbruck. It concerns the immunogenicity of Adalimumab and Certolizumab pegol and a comparison with Infliximab. The comparison of immunogenicity of the three drugs will be in different time intervals and doses. They are also going to study the long-term efficacy of Infliximab and antibody formation.

The study itself will be presented at the Congress in Lyon 2008.

The "Founding Father of ECCO", Renzo Caprilli from Italy, then announced the IBD Junior Club.

The aims of this club are to support education by courses, seminars, meetings and by using the Internet. It is also going to encourage and promote scientific research through common interest projects, and arrange training programs between hospitals and institutions of Young ECCO Members. The Club is going to create a new web page on the ECCO Website with IBD, up-dates, running scientific projects and information about the different exchange hospitals.

#### Vote by remote

For the next lecture the audience were given a remote control each.

Clinical debates were on the agenda, and the audience was requested to vote – which they did with these controls.



Herbert Tilg (far left) and Miquel Gassull presented the awards for the 10 best abstracts.

Before the debate they had to press their controls giving their opinion as to the correct answers to a set of eight questions. Then the debate was held, and after the opponents had presented their cases – and answered questions from both the panel and the audience – the same procedure was repeated.

The question now was to see if the debate had affected the opinions of the audience. As events unfolded, it seemed that the audience was quite stubborn and likely to stick to their first opinion...

#### Top-down or not

The first debate concerned top-down strategy – *Inverting the pyramid for UC and CD?* Geert D'Haens, Belgium, was the first speaker. He was in favour of starting at the top.

– With Infliximab it seems that we have been able to start extinguishing the fire of inflammation, Dr D'Haens stated.

– But we can't use a small watering can, we need a fire brigade and some water-bombing choppers!

His opponent, Jörgen Schölmerich, had a different view.

– We can do better with conventional methods, was his opinion.

– Patients with IBD are treated suboptimally. Take smoking for instance...

– The six-month results – remission – for all biologicals are between 23 and 30%. The use of immunosuppressants has increased – but so has surgery!

In the afternoon two more debates, following the same pattern, were held. Next topic was *Aggressive assessment of mucosa healing is mandatory* in which Daan Hommes, The Netherlands, was for and Marc Lemann, France, was against. *Should we attack the environment in IBD* was the last of these debates, with Stuart Bloom, UK, (for) and Gerassimos Mantzaris, Greece, (against).

#### Party

In the evening it was time for the ECCO-IBD Party.

This was held in Hall Dogana at the Congress Centre. This hall serves as a ballroom and its walls date back five hundred years. The Dogana also served as the exhibition hall during the Congress.

ECCO president Miquel Gassull made a speech, in which he thanked all the people behind the Organization for the meeting.

– I know the amount of work that's required to organize a meeting of this size. But now I hope that you can relax, he said to Herbert Tilg from the Local Organizing Committee.

He also handed out the prize that was awarded for the ten best abstracts sent to the Congress. It was a cheque for 500 Euro.

Then the band began to play and soon the dance floor was in full swing.

We spoke to one of the delegates, Dr Robert Löfberg from Sweden, and asked him for his view of the Congress so far. ➡





– It's great! It's such a good idea: To gather everyone that shares an interest in one disease – IBD – and dedicate a Congress to it. Therefore we have nearly a thousand people present here in Innsbruck. They want to learn about the latest findings relating to IBD. Here the overall high quality of the lecturers means that they are going to get that.

Dr Löfberg pointed to the debates as being particularly interesting.

– The remote controls for voting were a very good idea. It made the audience more involved. I enjoyed all the debates, but I have to appoint the top-down strategy debate as the most interesting of them all. It had such committed debaters.

#### Lively debate

The final day of the Congress saw some more of these debates with audience participation.

The first of these asked the eternal question of *Early surgery for UC?* Yves Panis, France, held the case in favour of this.

He drew attention to the fact that the mortality rate was very low (0.6%) and that several studies has shown that the quality of life had *not* been diminished for the patients who had been operated on – in spite of the fact that they themselves had expected it to be.

Gert Van Assche, Belgium, was against. He highlighted the quality of life significantly improved in patients receiving Infliximab.

The debate that followed became quite lively. Dr Van Assche admitted that some mortality over the years had been “caused by us when using steroids”.

They both agreed that a patient should be able to consult both a Physician and a Surgeon before a decision was taken.

The following debate was concerned with whether *Pediatric IBD should be treated more aggressively than adult IBD* or not. Salvatore Cucchiara, Italy, said yes and Stephen Murphy, UK, said no.

The final debate came back to the topic of surgery: *Cancer prevention: conservative medical or surgical approach?* Michael Kamm, UK, was Pro Medical and Al Windsor, UK, represented the Pro Surgical view.

After these three stimulating debates, Eduard Stange, Germany, and Simon Travis, UK, presented the ECCO Consensus report on Ulcerative Colitis.

– The guidelines are for guidance – not stipulation, Travis underlined.

– Empathy, care and concern will always be central tenets of care for ulcerative colitis and Crohn's disease, he summarized.

#### An amazing success

And then the Congress was over. There's no doubt that it was a success.

– This meeting is really such an amazing success – there are so many important people here, and the number of posters submitted is impressive, says Tillman Pearce from PDL BioPharma.

Eduard Caram also works for PDL BioPharma.

– We are developing a biological agent – Visilizumab – for severe ulcerative colitis. We had to go to large centres in 25 countries for studies, and that's where ECCO's infrastructure was of great value to us.

Caram points out that they are unique in their cooperation with ECCO.

– ECCO has developed a European wide infrastructure that increases our capacity to successfully execute complex trials, he explains.

#### A question of spirit

The collaboration with the industry has been very important, says Herbert Tilg.

– Schering-Plough, UCB and Abbott have been very interested in, proactive and supportive of the meeting.

We meet him just as the Congress has finished, and we have to ask him how he feels, now that it's all over.

– I feel very well. At the end of a meeting it's a question of spirit. The party we had yesterday reflected the spirit of the meeting.

He was the person who originally suggested Innsbruck for the Congress. It's here that Dr Tilg lives.

– I believed in Innsbruck. I knew we had the facilities that were necessary.

Dr Tilg thinks that ECCO still is in its early stage, and that more information about the organization needs to be spread.

–With this Congress we have created something that's valuable for the future – maybe a milestone, he concludes.

**PER LUNDBLAD**  
Senior writer



# 5th ECCO Course on IBD for Residents, Fellows in Gastroenterology and Junior Faculty

Now, becoming a “tradition” prior to the Second ECCO Congress in Innsbruck ECCO organized the well-recognized intensive IBD Course for Young Gastroenterologists for two days. Attendees were Young Gastroenterologists and IBD-ologists coming from all over Europe selected by the National Groups. The intense

course was a great opportunity to learn current concepts on pathogenesis, diagnosis, treatment and management of IBD at a European level, as well as contact important experts from the field of IBD in Europe, meet each other, get to know each other and hopefully be inspired to start or continue research in IBD and possible

to start cooperation with each other. According to the satisfaction survey, and the personal feedback from most of the students (see below) it met the expectations of the attendants.

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**PETER LASZLO LAKATOS**  
Co-Editor of ECCO News



Dear ECCO members,  
It is my privilege and honour to have been selected for this year's ECCO IBD Advanced Course for Young Gastroenterologists. I am pleased to report that this course was perfectly organized and that the courses were of highest level of quality, all concentrated in two days.

I would especially like to praise the interactive type of lectures and case presentations. This course was an excellent opportunity for young European gastroenterologists to make friendships with their colleagues and professors which can help in their careers.

This has ECCO course has an important value for developing countries, like Croatia, which are not yet members of European Union, for their integration into the IBD database network. I would like to thank educational committee presidents, prof. Boris Vucelic and prof. Pierre Michetti and Austrian organisers.

I would like to recommend to other young gastroenterologists to apply for future ECCO courses.

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**IVANA JUKIC, MD**  
Croatia



I found the course both challenging and very inspiring.

Challenging as my experience in treatment of IBD patients still is quite sparse so parts of the curriculum was new to me. Excellent lecturers who are really up-front in IBD research inspired both to improve the quality of my daily work and to keep on with my own research project. When coming home after the course I have tons of subjects I want to look closer into and need to learn more about, and

I know were to look for this knowledge. For me the most important result of the course though is that I feel more able to question the diagnostics, treatment and follow-up we practice at our hospital. Are the things we do really “up-to-date” or more a result of tradition? This question might be important not only to me but also to my colleagues...

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**MARTE LIE HOIVIK**  
Norway



I experienced the ECCO Course on IBD as an opportunity to further improve my knowledge on specific clinical aspects and problems, encountered during daily practice. The course focused largely on the clinical management of patients with IBD, referring to the recently developed ECCO consensus guidelines. Common and exceptional clinical cases were discussed with regard to these guidelines. The broad diversity of the participants' nationalities also displayed the differences in daily clinical care for IBD patients, again highlighting the need

for uniform consensus guidelines. The small-scale group of participants allowed intense interaction with the experts, who had excellent teaching skills and were all very accessible to open discussion. In view of the clinical character of the course, it is advisable to have some experience in treating IBD patients before applying for participation. All young colleagues dealing with IBD patients should have the opportunity to attend this excellent course.

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**TOM MOREELS, MD PHD**  
Belgium

# Dr Geert D'Haens in Belgium – secretary of ECCO

**Dr Geert D'Haens is one of Belgium's leading Gastroenterologists. He is also the Secretary of ECCO – in fact, he is one of the two people who created the Organization.**

**He works at Imelda Hospital and at Leuven University Hospital in Belgium. Dr D'Haens is a hard-working man with many things on his agenda.**

There are two decorations, facing each other on the opposite walls, in Dr Geert D'Haens office at Imelda Hospital in Belgium. They tell us a little bit about the background of the man himself.

## Cultural education

One is a framed version of the Hippocratic oath, and the other is the centrepiece of the famous Michelangelo painting from the Sixteenth Chapel where Gods finger met Man's thus creating the spark of life. Dr D'Haens went to a Jesuit school as a boy, and then he continued his education in high school in the Greek-Latin section.

– Such an education is good, because you learn about the background of your culture, he explains.

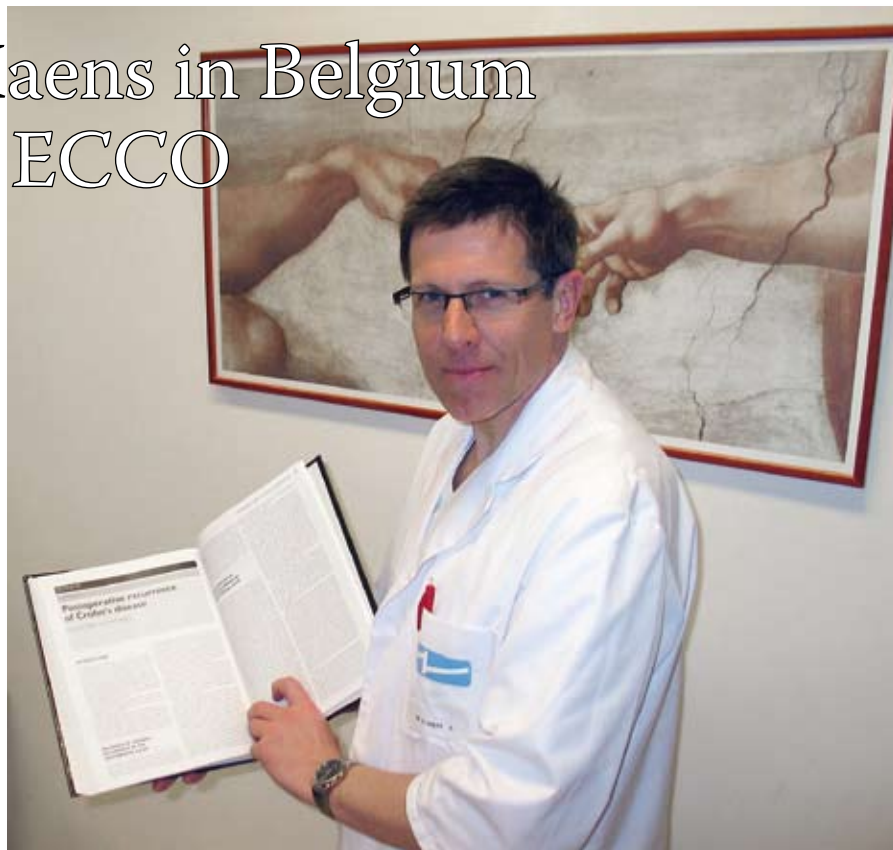
He also tells us that he had the honour of reading out the Hippocratic oath for his group at the ceremony that took place when they graduated from studying Medicine at the University.

His interest in cultural values is also manifested in the respect that he is a member of the Christian democratic think tank "Man and Society". He is also a board member for the Christian Democratic Party in the province where he lives in Belgium.

In his room we can also see portraits of his three daughters, and Dr D'Haens' intention is that they also in the future shall have the benefit of a classic education.

## Youngest hospital in Belgium

Geert D'Haens is 45 years old. So far he has received eight awards, he has published 95 papers and written 26 chapters in different textbooks. He is also one of the founders



of ECCO, and has been the Secretary of the organization since then.

We meet him on an ordinary day at work at Imelda Hospital in Bonheiden, a little town between Brussels and Antwerp. He works here four days a week. The fifth day he spends at Leuven University Hospital, where he sees IBD patients.

The Imelda Hospital is the youngest in Belgium. It was originally built for the care of TB-patients, but was rebuilt into the modern hospital we see today during the end of the sixties.

– We do everything here, including Cardiac Surgery – but not transplantations, Dr D'Haens says when he gives us a guided tour of the facilities for Gastroenterology patients.

## Long work weeks

Dr D'Haens is a Consultant Gastroenterologist. At Imelda there are a total of four Gastroenterologists and two Fellows. There are also four study nurses working in the GI Research Department.

– At Imelda we treat around 700–1,000 IBD patients, and this number is constantly increasing. We normally see a patient for life – *how* often depends on how aggressive the disease is. It could be every

other week or once a year. The latter is the minimum, Dr D'Haens says.

Dr D'Haens himself sees in total around 3,000 patients in a year. On a consultation day he sees between 30 and 35 patients, and on an endoscopy day he sees 20–25.

On the day when we are visiting, we follow Dr D'Haens when he sees patients, performs endoscopies and gastroscopies and checks things in the Study Department.

– I work normally 65–70 hours a week, Dr D'Haens tells us.

– One cannot produce papers during the day at the Hospital. Normally I go home around seven for dinner, perhaps watch the news and talk to my wife and children. After that I go in to my study, and I work for a couple of hours from home, before I go to bed.

## Simultaneous capacity

So there is no wonder that he has a tight schedule. But Dr D'Haens is good at coordinating and has the ability to do several things simultaneously. We get a glimpse of his ability for this, when he has a telephone conference.

This concerns a study of a new drug. Dr D'Haens is being informed about the proposed study, how it's going to be car- ➔

ried out and he finds it appropriate for the Study Department. The conference lasts about 25 minutes.

During this time he is also able to do other things – including checking his incoming mail.

The phone is very busy all day long, and several members of staff constantly enter the room with different requests. But Dr D’Haens is able to cope with all this, and to give his undivided attention to whatever is necessary at the time and to switch focus completely the next moment.

– I hate mediocrity he states, convinced that all patients deserve equal attention and that all commitments have to be met with care and perfection.

So the busy agenda doesn’t seem to be a problem for Dr D’Haens.

Actually, he seems to like it.

#### Several IBD trials

Patricia Geens, who is a Coordinator in the Study Department at the Hospital, shares this opinion. She knows Dr D’Haens well – he is the Manager of this Department.

– He has a lot of energy, she says when we ask her to describe Dr D’Haens.

– That’s the first thing that comes into my mind. He is a doctor that works very hard – but he *likes* to do it. He can’t sit still, he *has* to do different things and is always busy with many things at the same time.

– Dr D’Haens works very efficiently though, and is a good coordinator for us nurses, Patricia adds.

At the moment the department is running 13–14 trials. Most of these – around 10 – relate to IBD.

– We are participating in all of the big registration trials for the new drugs in IBD, and we are also spearheading a number of worldwide projects as lead investigators for new drugs, Dr D’Haens explains.

#### Growing

These studies are a growing part of the activity at Imelda Hospital.

– It’s really growing, Patricia says.

She started as a Study Nurse and Study Coordinator in 2003 at Imelda GI Clinical Research Center. Before Patricia, there was only one – Leen Stuyven.

– Then we have added one every year, so now we’re four in total. Leen and I work with IBD patients, and the other two – Do-



Patricia Geens (far right) and three of her colleagues at Imelda GI Clinical Research Center.

reen Iwens and Ingrid De Winter – work with GI Oncology patients.

– That we have been so successful at this is thanks to Dr D’Haens. He’s got so many contacts, he knows so many people. Another important factor is that he is secretary of ECCO. At the ECCO conferences – and other conferences as well – he meets the right people.

#### Learned a lot

Patricia worked as a secretarial assistant for Dr D’Haens in relation to his work for ECCO. She had this task for two years.

– I kept lists, organized names and invitations for the ECCO School. I undertook many of the practical aspects for the Organisation.

But these tasks grew, and were finally getting too big.

– Now VEREINT in Vienna manage all this including the finances for ECCO – and they are professionals. It got too big for me to handle on the side, Patricia says.

But she adds that she might be involved in the nurse’s school in the future, and that she never regretted taking on the work for ECCO.

– I learned a lot, and I met interesting people, she concludes.

#### Gastroenterology is varied

– I see myself as a clinician first, Dr D’Haens says.

– I am not involved in laboratory work at all any longer. I prefer to work with human beings – not with mice.

So why did he become interested in Gastroenterology in the first place?

– It’s so varied, with so many different diagnoses and organs – and measures of action, is his answer.

– Take Cardiology for example: They work on the same organ all the time. Another good reason is that, in Gastroenterology, the patients are often young. And I see them over a much longer period, sometimes for life.

#### IBD in USA

The specific interest in IBD stems from a year that Dr D’Haens spent in the USA.

– I was there in 1991–1992 to open up my view of medicine within the Anglo-Saxon world. There I met Dr Stephen Hanauer at the University of Chicago – the “Pope of IBD” in the world. He was my mentor, and he is still a good friend.

After the year in America, Dr D’Haens was invited to stay, but he decided to go back to Belgium. He further trained and worked with Paul Rutgeerts at the University of Leuven, a job that he still enjoys to date.

– My wife was pregnant, so we decided to go back home and I’ve never regretted that. I still get invitations to go back, but we are happy here, he explains. ➡



“ With the ECCO consensus and guidelines we can help to get away from the old habits in treatment. We question and challenge local habits, practises and dogmas.



**Accustomed to the stage**

Belgium has one of the highest incidences of IBD in the world.

– We don't know why this is so. It's always been like that, probably it has to do with genetic factors. Northern France also has a very high incidence rate.

Dr D'Haens' expertise in the field of IBD and his educational skills have made him an attractive lecturer.

– I decline two thirds of all the offers I get, but I like to lecture and to organize workshops for companies.

As a lecturer, Dr D'Haens has an effortless presence on the stage – you can tell that he feels confident there.

– When I was young, between 15 and 20, I was a member of a theatre and choreography group, and travelled through Europe as a dancer and an actor, he reveals.

– The experiences I gained then have been of great use to me when I appear on the stage.

**Biologicals are going to be more frequent**

At the ECCO Congress in Innsbruck, Dr D'Haens held “a case” for the benefits of the top-down strategy in a debate.

– Top-down is all about stratification of patients, he deems.

– How severe is the disease? I think top-down is going to be used for moderate to severe cases. To decide which is which, I still use my gut feeling. That's not scientific, but it's what I've got. With top-down treatment patients are getting free from symptoms, and we try to heal the colon, so therefore I believe this is the future. It would be wrong to go back to the old days.

Dr D'Haens is convinced that steroids are going to disappear in the future, due to side effects.

– That's a fact. But topical steroids – that act like a steroid in the gut – may continue to have a future.

He also believes 5-ASA have a future for use in Ulcerative Colitis – but not for Crohn's Disease except perhaps for the prevention of cancer.

Biologicals will be used more frequently according to Dr D'Haens, but they need to come down in cost.

– We still need long-term safety data. We have ten years of that now, but we need a lot longer.

**Challenge local habits, practises and dogmas**

ECCO was originally created after a spontaneous discussion between Geert D'Haens and Renzo Caprilli in Italy. Dr D'Haens has been the Secretary of ECCO since then, a position he intends to leave after the next ECCO Congress in Lyon, 2008.

– It's a good thing. An organization should revive its ideas and identity every now and then. If it doesn't do that, it soon turns into an “old men's club”, he explains.

So what has ECCO meant so far?

– To me it has been an exercise in building Europe. It's so exciting to sit at the same table as Serbs, for example. We also contribute to the quality of IBD care in less developed countries.

Dr D'Haens explains the importance of the ECCO consensus and guidelines.

– With these we can help to get away from the old habits in treatment. We ques-

tion and challenge local habits, practises and dogmas.

**Sports, music and literature**

In spite of his busy agenda, Dr D'Haens manages to find some time for relaxation.

– I try to find a balance between work life and family and friends. It's important to find time for my children. But that is something that goes for everyone – not just doctors, he points out.

He is very interested in sports, and has run the Marathons in both London and New York. He is also a keen mountaineer and has so far climbed Mont Blanc, Kili-manjaro and Island Peak in Nepal.

– We are a few old friends who climb a mountain every other year. Now we're planning for Argentina next year.

Dr D'Haens is also interested in music and literature.

– I'm very fond of the author Milan Kundera. When it comes to music I think that Bach is the best ever. I'm not a big connoisseur of pop music. I try to be a generalist – that is what education is all about: To keep your windows open and discover what else is out there.

And that statement seems to be a perfect way to sum up his character: Dr Geert D'Haens is a busy man indeed – he's busy finding new windows to open, in order to see what else there is on the other side.

**PER LUNBLAD**  
Senior writer

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**TOM ÖRESLAND**, Editor ECCO News

European Federation of Crohn's & Ulcerative Colitis Associations – EFCCA

# European empowered IBD patients in Seville

EFCCA Delegate Patients Education Conference & Annual General Assembly  
Seville, Spain 21–25 March 2007

Following the success of the October 2006 Paris annual meeting – see [www.efcca.org](http://www.efcca.org) – changes to the regulations governing NGO's registered under Belgian law necessitated an early EFCCA's 2007 annual meeting, which was held in Seville, 21–25 March with much appreciated support from the Falk Foundation.

As part of the overall 3+ full day programme EFCCA organised a medical and social related Patients Education Conference structured in such a way as to be able to emphasise the needs of people with inflammatory bowel disease and the benefits of empowerment, with outcomes assisting EFCCA's future work. Each of the conference plenary sessions involved both EFCCA delegates and visiting health professional's presentations, followed by interactive multi-stakeholder panels covering such topics as:

- **Quality of Life and Care with the right treatment**
- **Vision of the future, needs, information, partnerships and co-operation**
- **IBD and patient empowerment**

Professor Chris Gasche of Austria spoke about the latest advances in IBD-ology. Dr Moreira Dias of Portugal talked about Colorectal Cancer in IBD and Professor Salvador Pena of the Netherlands presented on the subject of Patient empowerment and Clinical Trials. Delegates valued the opportunity to hear from experienced international speakers and also learned much from the question and answer sessions. We were grateful to all for taking part and for their support.

In preparation for involvement in a IBD Patients Needs consensus project with the European Crohn's and Colitis Organisation – ECCO – delegate Iva Savanovic of HUCUK, Croatia, presented results of a brief introductory supporting EFCCA survey about Patient Info and Needs, which together with the earlier results of the 7 country EFCCA pan European IBD

patients questionnaire will also be available to the ECCO IBD Needs Consensus Project meeting of which EFCCA will be part. (*Copenhagen 26–27 March reported elsewhere in the ECCO newsletter*)

EFCCA Webmaster Salvo Leone from Italy provided a presentation about the value of the web illustrating part of his talk with slides about a "Crohn's and me" site and the increasing opportunities that are available for the patient associations to reach out.

The new Travelling with IBD (TIBD) files recently available from the EFCCA website at [www.efcca.org](http://www.efcca.org) were also presented. Although a "pilot" of 10 European member association English language files are available as of March 2007, further countries will be added over the coming months and local language TIBD info remains available from the national country associations.

Given the diagnosis of Celiac Disease in some patients with IBD contact has been established with the European Celiac Society and through the EFCCA Youth Group with the Celiac Youth of Europe. As a result although a representative was invited but unable to attend, EYG Leader, Marco Greco of AMICI Italy (*Marco was subsequently elected EFCCA Vice Chairman*), provided information about the Celiac movement together with a Celiac awareness presentation.

During the Seville days delegates were also able to be actively involved in the new EFCCA Standing Committees work relating to: Healthcare, Communication, Development and European Affairs. Many positive ideas came from the committee discussions and formal presentations were made in the **General Assembly** where decisions and/or support to move forward were also taken on a range of subjects ranging from the establishment of an EFCCA office with paid support/management, to enhancing EFCCA's interest in IBD Re-

search and working with ECCO on a range of initiatives. More outcomes can be seen in the fuller "Seville" report on the EFCCA website at [www.efcca.org](http://www.efcca.org)

In Seville on the evenings of 23–24 March we were able to join participants of the Falk Foundation's own symposia entitled "Intestinal Inflammation and Colorectal Cancer" and to meet with some of the EFCCA associations medical advisers, scientific committee members and other eminent health professionals and also join the social programme.

During the final Saturday afternoon the EFCCA Chairman accompanied by some delegates met with the local ACCU Seville Crohn's and Colitis patient association members during their local Doctor – Patient Seminar.

To conclude, the days in Seville proved busy, the General Assembly was positive, delegates constructive and forward thinking and the Patient Education Conference "pilot" a success.

For the year 2008 delegates accepted in the General Assembly that the EFCCA Patient Education Conference and General Assembly might be held in Dubrovnik 9–13 April and that it would provide an opportunity to invite to part of the programme representatives from the small national and local Crohn's and colitis patient groups throughout southern Europe, whose structure does not currently allow them full membership of EFCCA. A wide-ranging IBD Patient Information Exhibition is envisaged alongside the EFCCA Patient Education Conference. We thank the Board of the Croatian Crohn's and Colitis Association – HUCUK – for their initial assistance in enabling EFCCA to start planning their 2008 annual meeting in southern Europe. Watch the EFCCA website for further news.

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**ROD MITCHELL**  
Chairman EFCCA  
April 2007



| Congress   | Date                                  | Venue                              | Further information   |
|--|---------------------------------------|------------------------------------|---|
| <b>International</b>   |                                       |                                    |   |
| ASNEMGE 4th Summer School of Gastroenterology  | 21–24th of June, 2007                 | Prague, Czech Republic             | www.asnegmge.org  |
| 2nd Annual European Congress: Perspectives in Inflammatory Bowel Diseases                                    | 22–23rd of June, 2007                 | Brussels, Belgium                  | www.imedex.com/announcements/279.asp?utm_source=home_upperleft&utm_medium=banner&utm_campaign=279 |
| 9th World Congress on Gastrointestinal Cancer  | 27–30th of June, 2007                 | Barcelona, Spain                   | meetings@imedex.com   |
| GI Disorders   | 8–13th of July, 2007                  | Kiawah Island, SC, United States   | jnorton@mail.mcg.edu  |
| ICMI 2007 – 13th International Congress of Mucosal Immunology  | 9–12th of July, 2007                  | Tokyo, Japan                       | www2.convention.co.jp/icmi2007/pdf/ICMI2007_2ndAnnounce.pdf                                       |
| General Surgery & Gastroenterology Coding and Reimbursement Conference                                       | 12–14th of August, 2007               | Orlando, FL, United States         | www.docguide.com/crc.nsf/congresses/  |
| UOAA – The United Ostomy Associations of America National Conference   | 15–18th of August, 2007               | Lincolnshire, IL United States     | www.uoaa.org/conference_2007.shtml  |
| 13th Annual Hepato-Biliary Update and optional Hepatology Review for GI Board                                | 31st of August–2nd of September, 2007 | Paradise Island, Bahamas           | gwerner1@jhmi.edu   |
| Mayo Clinic Gastroenterology & Hepatology Board Review   | 6–9th of September 2007               | Chicago, IL, United States         | cme@mayo.edu  |
| World Congress on Gastrointestinal Cancer: 8th Annual Perspectives in Colorectal Cancer                      | 7–8th of September, 2007              | Miami, FL, United States           | meetings@imedex.com   |
| European Society of Coloproctology (ESCP) Second Scientific and Annual General Meeting                       | 26–29th September 2007                | Malta                              | www.escp.eu.com/malta/index.php   |
| ACG 2007: American College of Gastroenterology Annual Scientific Meeting and Postgraduate Course             | 12–17th of October, 2007              | Philadelphia, PA, United States    | www.docguide.com/crc.nsf/congresses/  |
| Internal Medicine: Focus on Gastroenterology   | 17–24th of October, 2007              | Fort Lauderdale, FL, United States | sandra@continuingeducation.net  |
| 15th UEGW  | 27–31st of October, 2007              | Paris, France                      | www.uegw.org  |
| Case Based Approach to the Management of Inflammatory Bowel Disease  | 3–4th of November, 2007               | San Francisco, CA, United States   | info@ocme.ucsf.edu  |
| Frontiers in Intestinal and Colorectal Disease Fifth Annual Congress A Multidisciplinary Approach            | 28–30th of November 2007              | London, UK                         | www.stmarkshospital.org.uk/Files/St%20Mark's%20Flyer.pdf  |
| 2007 CCFA National Research and Clinical Conference – 6th Annual Advances in the Inflammatory Bowel Diseases | 7–9th of December, 2007               | Miami, Florida, United States      | www.advancesinibd.com   |
| Gastroenterology at Sea  | 26th of March–9th of April, 2008      | Osaka, Japan                       | cruises@seacourses.com  |
| ACG 2008: American College of Gastroenterology Annual Scientific Meeting and Postgraduate Course             | 3–6th of October, 2008                | Orlando, FL, United States         | www.docguide.com/crc.nsf/congresses/  |
| <b>Czech Republic &amp; Slovakia</b>   |                                       |                                    |   |
| IBD symposium during The National Congress of Gastroenterology   | 7th of September, 2007                | Brno                               | jelena.vavrova@vfn.cz   |
| 6th Postgraduate Intensive IBD Course  | 4–5th of December, 2007               | Prague                             | jelena.vavrova@vfn.cz   |
| <b>Germany</b>   |                                       |                                    |   |
| Minimally Invasive Techniques in Gastric Surgery   | 9th of July–10th of September, 2007   | Norderstedt                        | info@esi-online.de  |
| DGVS - 62. Jahrestagung der Deutschen Gesellschaft für Verdauung und Stoffwechselkrankheiten                 | 12–15th of September, 2007            | Bochum                             | www.dgvs.de   |
| Falk 160-162 Gastro-Congress   | 10–14th of October, 2007              | Dresden                            | www.falkfoundation.com  |
| <b>Italy</b>   |                                       |                                    |   |
| IBD Congress and Course  | 14–15th of December                   | Milan                              | maurizio.vecchi@unimi.it  |
| <b>Latvia</b>  |                                       |                                    |   |
| III Latvian Gastroenterology Congress  | 10th of November, 2007                | Riga                               | http://www.kongresu-nams.lv   |
| <b>The Netherlands</b>   |                                       |                                    |   |
| First ICC (Initiative on Crohns and Colitis) symposium   | 26th of September, 2007               | Amersfoort                         | r.vd.hoeven@tramedico.nl  |
| Autumn National Congress for Gastroenterology  | 4–5th of October, 2007                | Veldhoven                          | secretariaat@nvge.nl  |
| <b>United Kingdom</b>  |                                       |                                    |   |
| Association of Coloproctology of GB & Ireland  | 2–5th of July, 2007                   | Glasgow                            | www.acpgbi.org.uk   |



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