



EUROPEAN CROHN'S & COLITIS ORGANIZATION

2007 VOLUME 2

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- The Austrian IBD Working Group
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ECCO NEWS

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

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EDITORIAL Letter from the President

ECCO News is getting into its objectives of being one of the best tools to maintain the European G-I community informed about the scientific and educational activities done by ECCO along the year. The task performed by *ECCO News* Editorial Board: Tom Öresland, Peter Latakos and Milan Lukas, as well as that of the Publisher Mediahuset is remarkable.

This issue of ECCO News is going to be distributed throughout the majority of European Countries. In addition new countries have applied to become members of ECCO; this is why I think it is worthwhile to go again through the changes ECCO will be involved in the near future.

Due to the increasing number scientific and educational activities, the Governing Board took important decisions which will affect ECCO organisation and structure. Since some of these decisions involve changes in the actual ECCO statutes, they were explained and proposed to the Assembly of Representatives of National IBD groups during the meeting held in Berlin prior to the UEGW. Once their inputs taken, the proposed changes in the statutes will be brought to the General Assembly during the forthcoming UEGW in Paris for their final approval and finally, if accepted, to the General Assembly during our 3rd ECCO Congress, IBD 2008 in France

In short; ECCO activities are steadily increasing, especially the number of studies, trials and courses, the IBDIS registry, the incorporation of the European Collaborative-IBD Group (EC-IBD) as full ECCO member with a seat in the Scientific Committee and last, but not least, the establishment of a yearly Congress. With all these together, the daily management of ECCO has become a complex issue, far from the possibilities, capabilities and time disposal of the Governing Board and Committee members. For this reasons ECCO has engaged an Association and Conference Management Company to be professionally managed. With this move, ECCO is establishing a long-term developing plan and design new strategies for our society and overcome the potential problems that may arise with the renewal of positions in the different committees and in the board.



President MIQUEL GASSULL Badalona, Spain

The second important item is the establishment of an open ECCO membership for all those interested in IBD. Registered members, in addition of the inherent benefits to the membership fee, such as lower registration rate in the congress and access to ECCO publications, will have the opportunity to influence ECCO's policy by expressing their opinions and criticisms at the General Assembly, with all the rights of a membership of a scientific society such as becoming candidates to be elected for ECCO positions. The Council of National Representatives will maintain its role as a consulting body for the Governing Board. Finally, ECCO has decided to launch its own Scientific Journal The Journal of Crohn's and Colitis (JCC) which will publish four issues per year. With this last decision, ECCO settles, together with the educational activities (courses) and the Congress, the third pillar to give full stability to our scientific society.

The Open ECCO Membership will be fully working from 2008, and those interested to receive information and show interest in being a registered member can request the appropriate form at ecco@vereint.com Those showing the interest in becoming ECCO registered members (through the provided form), will receive a complimentary free subscription to the *Journal of Crohn's and Colitis (JCC)* during 2007.

As can be seen the next months will be of tremendous activities for those working in ECCO committees and for the Governing Board. For these reasons, some committees have been enlarged (educational) or sub-committees have been established to cope with the setting of the new activities and the new management structure.

The Governing Board will keep you informed about the development of these events and looks forward to your collaboration as well as to your inputs and criticisms.

> MIQUEL GASSULL President of ECCO



his is the third issue of ECCO NEWS and for the first time the magazine is distributed in the majority of European countries. The European Crohn's and Colitis Organisation has been active for six years now and last year we saw the opportunity to start a newsletter.

Since this issue is reaching a considerable number of gastroenterologists throughout Europe that might not yet be aware of ECCO, we are reprinting the goals and activities of ECCO as described by our secretary Gert D'Haens. The newsletter has the aim of being an IBD voice in Europe giving information primarily but not only on what is going on in ECCO. Standards of care in European IBD are improving and becoming more and more uniform. Also to this end we need a forum for exchange of ideas and information. As you can read in the introductory article, ECCO has wide goals and is not an organisation exclusively for gastroenterologists; we would like to welcome surgeons, paediatricians, pathologists, basic scientists, nurses and any other person with an IBD interest. The European IBD patient organisation is also associated to ECCO and their leader Rod Mitchell will present the EFCCA in this issue. Furthermore you will find information on some of the multicenter IBD studies that are ongoing within the ECCO framework.

As a result of the ECCO organised gastroenterology courses, young gastroenterologists throughout Europe have had the opportunity to meet and start forming international networks early in their career. This has also resulted in the formation of Y(oung)ECCO - and you will find a report of their activities. In every issue of the newsletter one of the national IBD groups will present themselves; in this issue the turn has come to Austria. European IBD profiles will also be presented. We have had articles on our highly esteemed chairman, Miquel Gassull from Badalona, Spain and on "the man with the defensins", Eduard Stange from Stuttgart. In this issue you will find a presentation of a hard working British doctor from Oxford, Simon Travis, who has a very good name, especially among surgeons. Simon and Eduard have been responsible for the ECCO consensus on Crohn's disease that has already been published (Gut. 2006 Mar;55 Suppl 1) and for the forthcoming UC consensus that will be formally presented at the annual ECCO congress this year in Innsbruck. Next year the ECCO congress will be held in France in March under the auspices of our president-elect Jean-Frederic Colombel.

As for all newspapers, the success of ECCO NEWS is dependant on its readers. Having just started we would very much appreciate input from you with suggestions on how to be better. We would be very hap-

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py to have letters to the editor – hopefully provocative, but also informative! A debate on IBD related issues ongoing in the ECCO NEWS would be appreciated.

My co-editors are Milan Lukas in Prague and Peter Lakatos in Budapest. For those of you who feel uncomfortable writing in English, approach any one of the editors and we will try to offer some assistance. If you or someone else you know are not yet receiving the paper just pop an email with your surface mail address to ecco@mediahuset.se and you will be on the mailing list receiving ECCO NEWS free of charge.



Milan Lukas



Peter Lakatos



TOM ÖRESLAND Editor

The material published in this newsletter is the sole responsibility of the individual authors.

NEWS FROM THE SECRETARY

News from ECCO's General Secretary Geert D'Haens

The last few months have been really busy at the ECCO secretariat.

We had mainly to focus on the transfer of the permanent secretariat to Vereint, an association management company based in Vienna. Sonja Rosenzweig [ecco@vereint.com] will be our ECCO contact person at the office. Sonja will work in close cooperation with myself and has already taken over most of the duties of Patricia Geens.

Vereint will be responsible for the membership follow-up, organization of the general assembly and the governing boards and coordination of the activities of the other committees.

One of the important challenges will be the start-up of individual membership of ECCO which shall be launched later in 2007 and 'officially' start in 2008.

In the meantime, much of our energy also went to the preparation of the ECCO-IBD meeting in Innsbruck. Not only did we organize the students' course (this year for the 5th time!), but also (for the first time!) the nurses' meeting and the important gathering 'ECCO meets the industry', where expectations and ideas for

the future are exchanged between ECCO responsibles and our partners from the industry.

Cooperation with the biomedical industry is of vital importance for the longevity and success of ECCO. I sincerely wish to thank the efforts and the credit we have received to keep the IBD field in Europe one of the most exciting areas for research and international cooperation.

> GEERT D'HAENS General Secretary



Goals and activities of ECCO

GEERT D'HAENS MD, PhD Secretary of ECCO

ECCO is a non-profit scientific organization which was founded in Vienna in 2001. Its background was the great European idea of international collaboration on the 'old continent'. Virtually every country in Europe had 'national' or 'regional' study groups interested in the field of inflammatory bowel disease. The majority of European countries, however, were too small to set up ambitious scientific projects resulting in a significant impact on medical practice. As of today, ECCO counts no less than 24 membercountries.

The goals of ECCO

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

ECCO's Governing Board 2006

President: *Miquel Gasull*, Spain (mgassull.germanstrias@gencat.net) Past-president: *Renzo Caprilli*, Italy (renzo.caprilli@uniroma1.it) President-elect: *Jean-Frédéric Colombel*, France (jfcolombel@chru-lille.fr) Secretary: *Geert D'Haens*, Belgium (geert.dhaens@imelda.be) Treasurer: *Herbert Tilg*, Austria (Herbert.Tilg@uibk.ac.at) Chairman educational committee: Boris Vucelic, Croatia (boris.vucelic@zg.tel.hr) Chairman scientific committee: Daan Hommes, the Netherlands (d.w.hommes@lumc.nl)

Corporate sponsors 2006 (alphabetically):Abbott LaboratoriesGiven ImagingCellerixPDL BioPharmaCentocor, Inc.Schering AGDr. Falk PharmaSchering-PloughFerring InternationalShireGiuliani PharmaUCB S.A.Otsuka Pharmaceutical Europe, Ltd.

Benefits that ECCO offers to its sponsors:

- Invitation to the regular scientific meetings where original work of young European researchers in IBD is presented and discussed and to the annual general assembly.
- Scientific advice in the organization of meetings by pharmaceutical companies. Upon requests by our industrial partners, we appoint 'ad hoc' committees that will be of assistance in the preparation and the program building for any IBD-related meeting, beit local, national or international.
- Assistance in the development of clinical trials throughout Europe. For this purpose the scientific committee developed a 'Who's who' manual.

ECCO's scientific activities

Coordination and initiatives are in the hands of the Scientific Committee (Sci-COM) led by Daan Hommes. Yehuda Chowers (Israel), Walter Reinisch (Austria), Simon Travis (United Kingdom) and Severine Vermeire (Belgium) were appointed by the Governing Board and the Chairman of the SciCOM to join the five-member committee. Pia Munkholm has recently joined the committee as a representative of EC-IBD. In order to achieve its ambitious target, the SciCOM made an inventory of all



ECCO members, by means of a "WHO-IS-WHO" book which was published in April, 2005. This will be of great help for the organization of scientific projects and after implementation in ECCO's homepage for rapid electronic communication between SciCOM and the centres. Building on its "WHO-IS-WHO" the SciCOM will also assist the biomedical industry in their selection process of clinical trial centres. In this respect, the first collaborations have been initiated. The content of the network will be up-dated every few years, since centres will enhance their level of research and expertise in the near future.

Scientific projects anno 2006

– Autologous stem cell transplantation in Crohn's disease, a randomized controlled trial. All information to be found:

 – Pregnancy outcome in IBD: multicenter, prospective case-control study

 – IBDIS, an IBD information system (www.ibdis.net)

– Publication of management guidelines for Crohn's disease: The results of the first consensus conference, sponsored jointly by ECCO and the Robert Bosch foundation, were published as 3 papers in GUT in the spring of 2006. The 3 papers have become the most frequently consulted papers of the year of this journal.

Given the success of this meeting, a second consensus conference, this time on diagnosis and management of ulcerative colitis, will be organized in BERLIN prior to UEGW.

ECCO's Research fellowship

From 2006 onwards, the annual deadline for submission for the ECCO Fellowship will be December 1st. Applicants should be aware that these awards are offered to promote and encourage innovative research in inflammatory bowel diseases by young and enthusiastic scientists. A total amount of 30,000 \in will be awarded for a duration of one year. Details on the ECCO fellowship are to be drawn from the ECCO homepage.



Current membership and national representatives See page 32.

ECCO's educational activities

Annual advanced IBD course for fellows and junior faculty

One of the first successful initiatives by ECCO was the organization of an advanced IBD clinical course for fellows and junior gastroenterological faculty. The course has already been organized 4 times (In Prague 2003, Dubrovnik 2004, Sardegna 2005 and Amsterdam 2006). Every course was attended by over 40 students selected from all over Europe. This international gathering offered an excellent opportunity for young researchers and clinicians to meet colleagues from all the member-countries and to establish further exchange and friendships. Selection of participants is organized by the national representatives.

ECCO's cooperation with patient organizations and other IBD organizations

A permanent seat in ECCO's general assembly is occupied by a representative of EFCCA, the European IBD patient association (European Federation of Crohn's and Colitis Associations): (www.efcca.org).

In addition, ECCO is establishing cooperation with 'international organization for inflammatory bowel diseases' IOIBD, a worldwide group of IBD experts. One of the first joint projects is a scientific paper on 'endpoints for clinical trials in ulcerative colitis', expected to appear later in 2006.

ECCO in UEGF and UEGW

A member of ECCO's scientific committee, currently Dr Walter Reinisch from Vienna Austria, is part of the scientific committee of UEGW, which designs the program of the UEGW. The program is now characterized by a strong presence of IBD lectures and fora.

In addition, ECCO holds a seat in the governing board of UEGF as an 'associate member'.

ECCO has also a seat in the Educational Committee of UEGF.

What's going on at ECCO today?

2006 has been an important landmark year for the development and professionalization of ECCO. The year started with the first European IBD congress in Amsterdam, which was a true success with full rooms and meeting halls until the last minute. A big party was organized to celebrate the fifth birthday of the organization.

During the meeting, the governing board met with all the industrial partners to discuss their expectations and wishes for the future. In addition, a 'corporate meeting' was held, where the sponsors were free to give an overview of their current developments and plans.

The students' course in Amsterdam led to the creation of the 'ECCO juniors' club'.

Furthermore, an important decision was taken by the governing board to put the permanent secretariat of the organization in the hands of a professional organization specialized in association management and global congress organization. They will not only take care of the daily secretarial issues, but will also organize future congresses and educational activities for ECCO.

One of the first challenges for this professional organization is the implementation of individual membership. All individuals with specific interest in IBD will be given the opportunity to become a member of ECCO and receive a number of services including access to website (member-only section), ECCO News, reduced fee for the congress, attendance of activities restricted to members, inclusion in WHO's WHO and later probably free subscription to a European IBD journal.

This membership will be offered via the website at very democratic rates starting January 1, 2007.

Another major achievement of ECCO in 2006 was the publication of the consensus on Crohn's disease, based on a meeting which was organized in the fall of 2004 in Prague. The writing process took practically a full year and the whole project was coordinated by the professors Simon Travis from Oxford and Eduard Stange from Stuttgart. The three papers in GUT are amongst the most frequently referenced papers of the year!

New challenges

New and important challenges await ECCO in the near future and in 2007: the organization of the consensus meeting on ulcerative colitis in Berlin, October 2006, the organization of the second IBD congress in Inns-

The three papers in GUT are amongst the most frequently referenced papers of the year!

Stange EF, Travis SP, Vermeire S, Beglinger C, Kupcinkas L, Geboes K, Barakauskiene A, Villanacci V, Von Herbay A, Warren BF, Gasche C, Tilg H, Schreiber SW, Scholmerich J, Reinisch W; European Crohn's and Colitis Organisation. European evidence based consensus on the diagnosis and management of Crohn's disease: definitions and diagnosis. Gut. 2006 Mar;55 Suppl 1:11-15.

Travis SP, Stange EF, Lemann M, Oresland T, Chowers Y, Forbes A, D'Haens G, Kitis G, Cortot A, Prantera C, Marteau P, Colombel JF, Gionchetti P, Bouhnik Y, Tiret E, Kroesen J, Starlinger M, Mortensen NJ; European Crohn's and Colitis Organization. European evidence based consensus on the diagnosis and management of Crohn's disease: current management.Gut. 2006 Mar;55 Suppl 1:116-35.

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bruck, March 2007 with for the first time original scientific material that will be presented, the fifth advanced IBD course for junior gastroenterologists and the first IBDnurse course, a number of new projects with the industry that will be launched in 2007, closer cooperation with the patient association EFCCA and definitive installation of the secretariat in Geneva.

Finally, ECCO News (of which you are reading the first issue), will become an important way to distribute information on ECCO activities throughout Europe.

Please become an ECCO member – all information via the website soon!



GEERT D'HAENS



Restore[™] therapeutic alternatives to Refractory Severe UC patients

Bringing more treatment options to the most severe IBD cases, and more particularly to patients with fulminant UC, is an important target for the IBD community. A unique partnership concluded between ECCO and PDL BioPharma paved the way to a novel and productive drug development program, which ensures with feedback from acknowledged experts, that trials are correctly designed toward the correct group of patients and that participation is offered to patients in different parts of Europe.

evere ulcerative colitis is estimated to affect 15% of patients during the course of their disease, and until the introduction of appropriate medical and surgical therapy it was associated with a mortality of 30%. As reminded by the latest ECCO consensus, patients hospitalized with severe/fulminant UC are given IV steroid as a mainstay. However 40% of patients fail IV steroids and require rescue medical therapy or proctocolectomy.

In a large survey conducted by the European Federation of Crohn and Colitis Association "87% (of interviewed patients) are willing to switch treatment before facing surgery". For the calcineurin inhibitor cyclosporin and the chimeric anti-TNF antibody infliximab the use as a last resort before surgery is supported by placebo controlled evidence. Unfortunately, beneficial effects are not always durable and after initial improvement with cyclosporine, up to 65% of patients relapse after 1 year, 90% after 3 years and up to 88% of patients require colectomy within 7 years1. Long term colectomy data with infliximab are not yet available. Decision to move to colectomy is a serious choice that must be endorsed by a multidisciplinary team and reserved for patients with no other therapeutic option.

There is a clear need to develop different approaches and tailor new trials toward IV Steroid Refractory patients (IVSR). By targeting the CD3 antigen (T-cell receptor), visilizumab (Nuvion®), a humanized monoclonal antibody, has shown to selectively induce apoptosis of activated T cells, the cells believed to fuel the inflammatory cascade in UC. Unlike infliximab, visilizumab has a short half-life and is dosed on two consecutive days avoiding the need of continuous maintenance with a biologic.

Two open label, dose finding studies in the US and Europe have suggested efficacy of visilizumab in severe steroid refractory UC. By inducing T-cell apoptosis, administration of this agent causes some degree of cytokine release syndrome in most patients treated, but this can be managed by appropriate pre-medication and appears to be dose dependent.

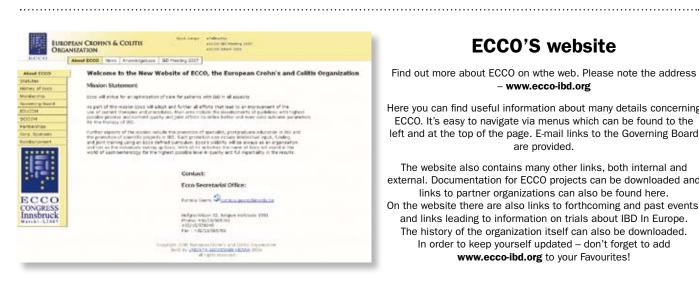
Based on these initial studies, PDL BioPharma, in partnership with ECCO, is enrolling patients in two phase 3 placebo controlled clinical trials. It is the first time that ECCO entered such an agreement and this has allowed the Restore[™] studies to obtain optimal study site selection in Europe.

Novel in this partnership is also that the ECCO Scientific Committee members serve as regional coordinators for each participating country. National coordinators, overlooking the Restore[™] trials in every individual country, report to the ECCO regional coordinators and discuss outstanding issues. This organization has also shown to potentate recruitment and communication channels with the geographically disperse investigators and the sponsor. With a swift recruitment and a carefully conducted study program, patients and physicians will be able evaluate the therapeutic potential of visilizumab early 2008.

1. Moskovitz DN, van Assche G et al. Clin Gastroenterol Hepatol 2006 Jun; 4(6):760-5.



GERT VAN ASSCHE and SÉVERINE VERMEIRE University of Leuven Hospitals



ECCO'S website

Find out more about ECCO on wthe web. Please note the address – 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 to your Favourites!



Inflammatory Bowel Disease and Pregnancy: a prospective European case-control study

nflammatory Bowel Disease (IBD) com-

monly affects women during the reproductive years and the impact of these diseases on pregnancy outcomes is a significant concern for patients.

The patients, worried about pregnancy, ask their physicians mainly these questions:

- * What are the effects of IBD on pregnancy?
- * What are the effects of pregnancy on IBD?
- * What treatment is appropriate and safe for the foetus?

Many studies dealed with these issues, nevertheless data are insufficient or still controversial.

Therefore a large multicenter prospective study aimed to evaluate the outcomes of pregnancy and the disease course in a group of European pregnant women with Ulcerative Colitis (UC) and Crohn's Disease (CD) seemed a perfect opportunity to evaluate all the parameters about IBD and pregnancy.

So, after a presentation of the project and after a discussion with the ECCO Members, the study started in January 2003.

Sixty-nine Centers in thirteen Countries joined the project (see table 1).

Pregnant women with UC and CD, seen at these 69 Gastroenterology Units, were followed-up and compared to controls in General Population (GP). All the patients were interviewed, during pregnancy and in the post-partum period (6 months after delivery) every three months.

For the control group we collected, prospectively, one pregnancy, in General Population ("GP control group"), for each patient's pregnancy, matched for maternal age at conception (\pm 5 years) and gravidity (defined as the number of previous conception).

To investigate the influence of the pregnancy on IBD we compared the course of the disease in pregnant and in nonpregnant IBD patients ("control patients group"). Non-pregnant control patients were matched to the pregnant patients with CD and UC were followed-up during the study period and interviewed every three months.

For all the IBD and controls pregnancies, the following parameters were evaluated: live births, birth-weight (low birth weight < 2500 g), congenital abnormalities, spontaneous and therapeutic abortion rates, pre-term deliveries (< 37 weeks of gestation), mode of delivery. In addition in the IBD group, we evaluated the course of the disease during pregnancy and in post-partum period and drug consumption at conception and during pregnancy. The interview will be made by a physician of the referral center using a standard questionnaire.

At the start of the study, in 2003, we plan to enroll about 500 IBD pregnant patients or, anyway, to stop the study after five years.

As of today we know that, overall, 565 IBD pregnant patients have been included (299 UC, 257 CD and 9 indeterminate colitis), then we stopped the recruitment at the end of December 2006.

The results of this European study will be presented at major Gastroenterology meetings.

Pregnancy is a very important event for every person. Discussion and education with regard to pregnancy is an essential part of the management of young person with IBD. Treating patients with IBD who want to become pregnant or are pregnant involves specific management challenges.

In order to answer patients' questions the clinician needs evidence.

The study results, with particular regard to treatment, will be useful, not only for

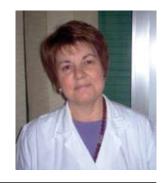
Table 1.

69 Centers in 13 Countries participating in the study

Nation	Center (n.)	Pts enrolled
Austria	1	29
Belgium	3	19
Denmark	1	44
England	1	3
Germany	4	11
Greece	1	5
Ireland	1	14
Italy	50	376
Latvia	1	1
Portugal	1	3
Spain	3	42
Switzerland	1	9
The Nether- lands	1	12

the clinicians, but also for the IBD patients' associations to answer any question about IBD and pregnancy.

Finally I would like to thank first of all the ECCO for the approval to carry out the project, then everyone involved in the study in each participating center . Thank you all!



AURORA BORTOLI On behalf of the European Crohn's and Colitis Organisation (ECCO)



The IBDchip European Project

Project Full Title: Usefulness of a new DNA array (IBDchip) to predict clinical course, development of complications and response to therapy in patients with inflammatory bowel disease (IBD)

The *IBDchip European Project* is a ninepartner collaboration between leading European researchers and knowledge intensive companies which started in December 2006 and is co-funded by the European Commission under the Sixth Framework Programme. The main aim of the project is to provide doctors, for the first time, with a non-invasive, predictive tool to optimize treatment in IBD patients.

very physician with experience in the treatment of patients with ulcerative colitis (UC) and Crohn's disease (CD) is well aware that these are very heterogeneous conditions. Disease location, phenotype, severity, the presence or not of extraintestinal manifestations and the likelihood of responding to a variety of therapeutic options varies greatly from patient to patient.

There is a growing body of evidence proving that genes play a key role in the pathophysiology of IBD and pointing towards a polygenic mode of inheritance for CD and UC. However, to date, studies have only addressed the influence of single mutations on IBD resulting in poor prediction of clinical course or response to therapy in individual patients.

The IBDchip is a DNA chip on a glass support initially developed in Spain. The first version of the IBDchip was able to analyze the presence of 61 SNPs located in 40 genes. These SNPs were selected, after thorough literature review, for their potential impact on IBD susceptibility, phenotype/clinical course or response to therapy. A local Spanish study involved almost 900 patients divided in two separate cohorts in order to develop/validate several predictive models (one for each clinical outcome). The final statistical analysis of the Spanish Study is expected to be complete in 2–3 months.

"IBDchip EU Project" basic facts and figures:

- Total Budget € 3.5 million
- EC Contribution € 2.4 million
- Duration 3 years
- Start date December 1st 2007

The IBDchip is a DNA chip on a glass support initially developed in Spain.

Taking into account the vast heterogeneity of the genetic background across Europe, the IBDchip European Project was conceived not only as a much bigger study (4000-5000 IBD patients will be included), but also to allow the inclusion of patients from different European regions. To achieve this aim, partners from 7 European countries (UK, Germany, Holland, Belgium, Italy, Czech Republic and Spain) will include patients. Another key difference from the pilot Spanish study is that the new version of the IBDchip that will be used in the EU Project will be able to simultaneously analyze around 200 SNPs.

The IBDchip European Project is structured in several retrospective and prospective studies, to ascertain the usefulness of the IBDchip to predict disease behaviour and response to therapy in patients with UC and CD. In addition to these core studies, the Project will also include other lines of research to develop a new scanner (characterized by a significant improvement in size, speed and cost), analyze the ethical and legal issues, and characterize the pathways towards routine use of the IBDchip. Partners:

- Coordinating centre: Hospital Clínic/ IDIBAPS, Barcelona, Spain: principal investigator – Miquel Sans
- 2. Progenika Biopharma SA, Bilbao, Spain: principal investigator – Marta Artieda
- 3. Innopsys SA, Carbonne, France: principal investigator – Stéphane Le Brun
- 4. University of Oxford, Nuffield Department of Medicine and Oxford GKP, Oxford, UK: principal investigator – Derek Jewell
- 5. The University Hospital in Leuven, Belgium: principal investigator – Severine Vermeire
- The Laboratory of Immunogenics, Department of Pathology, VUMc, Amsterdam, The Netherlands: principal investigator – Salvador Peña
- The Institute for Clinical Molecular Biology (ICMB), Kiel, Germany: principal investigator – Stefan Schreiber
- The University Hospital in Prague, Czech Republic: principal investigator – Milan Lukas
- 9. Istituto Clinico Humanitas, Milan, Italy: principal investigator – Silvio Danese

For more information regarding this project please contact: Dr. Miquel Sans Gastroenterology Department, Hospital Clínic / IDIBAPS Barcelona, Spain Ph: 34-93-2275418 Fax: 34-93-2279387 e-mail: msans@clinic.ub.es



DR. MIQUEL SANS Hospital Clínic/IDIBAPS Barcelona, Spain

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CONSENSUS ON ULCERATIVE COLITIS

THE ECCO CONSENSUS ON ULCERATIVE COLITIS

Evidence Based, not Eminence Based

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In October 2006, preceding the UEGW, the ECCO consensus conference on ulcerative colitis steered by Eduard F. Stange, Marc Lémann, Alastair Forbes and Simon Travis was held in Berlin. A set of 13 working parties covering the major topics from classification of ulcerative colitis to forms of treatment and surveillance had prepared statement proposals. These were based on expert opinion, quantified by a set of questionnaires which were answered by the participants and, crucially, a systematic literature search. During one and a half days of sessions a panel of the leading European experts discussed the statements vigorously and sometimes controversially, before reaching a consensus on the final versions. All but two were supported by a Consensus vote (>80%) and are now "chiselled in stone", i.e. off limits to changes by editors, reviewers or industry. During the next weeks an accompanying text will be provided by the working parties to explain and qualify the **Consensus statements and reference the** relevant literature. The final Consensus paper will be published in 2007. Consensus funding was provided by ECCO and the Robert Bosch Foundation.

•he former British prime minister Margaret Thatcher is quoted with the statement "we disagree, therefore we need consensus". This is all too true in a conference where an international panel of European experts with very different health care systems, scientific background, eloquence and willingness to compromise convenes. The experts included gastroenterologists, pathologists, surgeons, paediatricians, psychosomatic specialists and a patient representative. Many of the participants had already contributed to the ECCO Consensus on Crohn's disease held in Prague which was detailed in the full publication in the March 2006 issue of Gut (see last issue of the ECCO NEWS).

The experience of a positive outcome from the previous Consensus clearly shaped this conference. Although the consensus process was similar to that on Crohn's disease, some modifications were introduced. For example, to ensure a complete questionnaire return, only participants who answered these were invited to Berlin. Furthermore, the working parties were smaller and more effective. An additional set of senior experts not belonging to a working party were invited as voting members to balance the view. The statement proposals presented by the chairmen in Berlin were agreed by their working party prior to the plenary sessions and amended by the plenum through real-time changes to the wording on screen until a Consensus (>80% agreement) was reached. The list of participants and their respective role have already been given in the last issue of the ECCO NEWS. This article will focus on selected topics of the new Consensus.

Classification and diagnosis of ulcerative colitis

The working parties on classification and diagnosis were chaired by Severine Vermeire from Leuven, Belgium, and Walter Reinisch, Vienna, Austria, respectively. Classification covered four topics: disease extent, activity, age at onset and use of molecular markers. Clearly, the extent of disease influences patient management, for example by determining the optimal treatment modality (topical versus oral) or the start of surveillance. Therefore, a classification according to disease extent using the Montreal classification into proctitis, left sided colitis (up to the splenic flexure) and extensive colitis was supported by the consensus (Evidence level (EL) 5, recommendation grade (RG) D, see Table 1).

A classification with respect to disease severity was also considered useful for clinical practice (EL 1b, RG B), although present indices of disease activity have not been adequately validated. In contrast to disease extent and activity, age at onset was not considered useful for classification. No evidence based recommendation could be made to implement the routine clinical use of genetic or serologic markers for classification.

It was felt that a gold standard for the diagnosis of ulcerative colitis is not available. Rather, the diagnosis should be established by combination of medical history, clinical evaluation, typical endoscopic and histologic findings. An infective cause of the colitis should be excluded and re-evaluated after an interval if necessary. Symptoms are dependent upon extent and severity of the disease and most commonly include bloody diar-



Table 1

Levels of Evidence and Grades of Recommendation based on the Oxford Centre for Evidence Based Medicine.

Level	Individual study	Technique	
1a	Systematic review (SR) with homogeneity of Level 1 diagnostic studies	Systematic review (SR) with homogeneity of randomized controlled trials (RCTs)	
1b	Validating cohort study with good reference standards	Individual RCT (with narrow Confidence Interval)	
1c	Specificity is so high that a positive result rules in the diagnosis ("SpPin") or sensitivity is so high that a negative result rules out the diagnosis ("SnNout")	All or none	
2a	SR with homogeneity of Level >2 diagnostic studies	SR (with homogeneity) of cohort studies	
2b	Exploratory cohort study with good reference standards	Individual cohort study (including low quality RCT; e.g., <80% follow-up)	
2c		"Outcomes" Research; Ecological studies	
За	SR with homogeneity of 3b and better studies	SR with homogeneity of case-control studies	
Зb	Non-consecutive study; or without consistently applied reference standards	Individual Case-Control Study	
4	Case-control study, poor or non-independent reference standard	Case-series (and poor quality cohort and case- control studies)	
5	Expert opinion without explicit critical appraisal, or based on physiology, bench research or "first principles"	Expert opinion without explicit critical appraisal, or based on physiology, bench research or "first principles"	

Grades of Recommendation

Α	consistent level 1 studies
В	consistent level 2 or 3 studies or extrapolations from level 1 studies
C	level 4 studies or extrapolations from level 2 or 3 studies
D	level 5 evidence or troublingly inconsistent or inconclusive studies of any level

For details see http://www.cebm.net/levels_of_evidence.asp#refs

rhoea, rectal bleeding and urgency. Systemic symptoms of malaise, anorexia or fever are features of a severe attack. Initial laboratory investigation should include a full blood count, serum urea, creatinine, electrolytes, liver enzymes, iron studies and C-reactive protein. The latter, or the ESR, may also be helpful in monitoring the treatment response. Microbiological testing for infectious diarrhoea including Clostridium difficile toxin and, in severe or refractory disease, tests for Cytomegalovirus were recommended (EL 2b, RG B). For suspected ulcerative colitis, colonoscopy, preferably with ileoscopy, and segmental biopsies including the rectum are the preferred procedures to establish the diagnosis and extent of disease. Patients with a severe attack should have abdominal radiography and sigmoidoscopy as first line procedure. Typical endoscopic features are continuous and confluent colonic involvement with clear demarcation (EL 2b, RG B). Transabdominal ultrasound was considered to be of secondary value whereas current data do not demonstrate a diagnostic role for virtual colonography in this regard.

Treatment of active disease

This working party was led by Simon Travis. During the consensus conference the treatment of active disease was discussed according to site and activity of disease as well as course and behaviour. Therapy specific considerations concerning the different medications will follow in the final text. For proctitis mesalazine suppositories were recommended as the preferred initial treatment for mild or moderately active disease (EL 1b, RG B). Combining topical mesalazine with oral mesalazine or topical steroid may be more effective than either alone and should be considered for escalation of treatment. Left-sided active ulcerative colitis of mild to moderate severity should initially be treated with topical aminosalicylates (EL 1b, RG B) combined with oral mesalazine (EL 1a, RG A). Systemic corticosteroids were considered appropriate if symptoms of active colitis do not respond rapidly to mesalazine (EL 1b, RG C).

Extensive colitis should initially be treated with oral mesalazine (EL 1a, RG A), combined with topical mesalazine (EL 1b, RG A), because oral mesalazine



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alone induces remission only in a minority of patients. Systemic steroids again were considered appropriate if a rapid response is not obtained or in those who are already taking appropriate mesalazine maintenance therapy. Severe colitis of any extent is usually an indication for hospital admission for intensive treatment such as intravenous steroids (EL 1b, RG B). Monotherapy with ciclosporin was considered an option for patients intolerant of intravenous steroids. Severe cases should best be cared for jointly by a gastroenterologist and a colorectal surgeon to consider surgical options. Second line therapy with the calcineurin inhibitors cyclosporine or tacrolimus (EL 1b, RG B) or infliximab (EL 1b, RG B) were considered often to be appropriate in steroid non-responders. However, if there is clinical deterioration or no improvement within a further 4-7 days colectomy should (usually) be recommended. In outpatients with less active but persistent disease despite oral steroids treatment with azathioprine/mercaptopurine should be initiated (EL 1b, RG B), although surgical options as well as other medications (intravenous steroids, infliximab, calcineurin inhibitors) should also be considered. If refractory or intolerant to thiopurines, infliximab or surgical options should be discussed but continued medical therapy that does not achieve steroid free remission was felt to be inappropriate by the Consensus.

Maintenance treatment

The goal of maintenance treatment was defined by the working party, chaired by Marc Lémann from Paris, as to maintain steroid free remission clinically and endoscopically. It was unanimously agreed that maintenance treatment is indicated in all patients, with the exception of a few patients where disease extent is limited. Before starting maintenance treatment, remission should be confirmed clinically, but endoscopy is useful to confirm remission and adjust therapy. The choice of maintenance treatment should be determined by disease extent, disease course, failure of previous maintenance treatment, severity and treatment of the most recent flare as well as aspects of safety and cancer prevention. Oral 5-ASA containing compounds were suggested as the first line maintenance treatment in patients responding to

5-ASA or steroids (EL 1a, RG A). Maintenance with topical 5-ASA was considered a valuable alternative in proctitis and left sided colitis. A combination of both oral and topical 5-ASA can be used as a second line maintenance treatment (EL 1b, RG B). The minimal effective oral dose is 1.2–1.5 g/day and for topical treatment 3 g/week, although the doses can be tailored individually according to efficacy. Importantly, all available preparations of oral 5-ASA were considered effective and, because of less toxicity, superior to sulfasalazine.

Azathioprine maintenance treatment was recommended

- in patients responding to cyclosporine or tacrolimus for induction of remission
- * in those with early or frequent relapse or
- intolerance of 5-ASA
- * in steroid dependent patients
- as an option in patients responding only to intravenous steroids.

Interestingly, the Consensus suggested that addition of 5-ASA to thiopurines or continuation of oral 5-ASA can be recommended because of its possible additive and also cancer protective effect, although only with special attention to myelotoxicity (EL 5, RG D).

Surgery

Due to the scarcity of controlled trials in surgery, the surgical working party, chaired by Tom Öresland from Gothenburg, Sweden, had to rely less on high level evidence and more on uncontrolled experience than the "conservative" fraction. As a standard procedure, when performing a restorative proctocolectomy (IPAA) for ulcerative colitis a covering loop ileostomy was recommended although it might be avoided in selected cases (EL 3b, RG C). A staged procedure (colectomy first) was recommended in the acute case when patients do not respond to medical therapy (EL 4, RG C) and in a patient that has been taking 20 mg or more of prednisolone for more than 6 weeks (EL4, RG C). When performing a colectomy for ulcerative colitis in emergency circumstances, the whole rectum should be preserved (EL 4, RG C).

When performing an IPAA (ileopouchanal anastomosis) the maximum length of anorectal mucosa above the dentate line left below a stapled anastomosis should not exceed 2 cm (EL 4, RG C). In contrast, when the indication for surgery is cancer/dysplasia, proctocolectomy with anastomosis at the dentate line was recommended (EL 4, RG C), to minimise the risk of malignancy in the remaining colonic musosa. Pouch surgery was considered appropriate only in those centres performing more than 10 procedures/year. Salvage surgery for complications of IPAA should only be done in special centres with an adequately skilled staff and a reasonable number of procedures performed per annum (EL 5, RG D).

Follow-up should be individualised and focus on those patients with signs of chronic inflammation in their pouch mucosa. There are not enough data to give a recommendation on surveillance of pouches with respect to malignant changes. However, patients operated for cancer/dysplasia should be followed long term (EL 5, RG D). In a fertile female patient the option of an ileorectal anastomosis should always be considered, because fecundity is at risk after IPAA (EL 3b, RG B). Prednisolone 20mg daily or equivalent for more than six weeks is a risk factor for surgical complications (EL 3b, RG C). Therefore, corticosteroids should be weaned if possible. Preoperative azathioprine does not increase the risk of post-operative complications (EL 3b, RG C). Colectomy for ulcerative colitis immediately following or in the medium term after the use of ciclosporin appears to have no higher rate of postoperative complications (EL 2b, RG D), while there are no sufficient data yet available for infliximab.

Conclusion

A European Consensus on the management of ulcerative colitis was accomplished. The former ECCO Consensus on Crohn's disease has been well received on both sides of the Atlantic (Sandborn & Hanauer *Gut* 2006, commentary in press). It is hoped that both new Consensus will help guide practice in Europe and elsewhere. The European guidelines may also be used as a reference when the national guidelines are updated and it may act as a standard of current practice during the design of clinical trials.



The Austrian IBD Working Group

Concept by WOLFGANG PETRITSCH and WALTER REINISCH, edited by E. Lamont

History

The Austrian IBD Working Group within the Austrian Society of Gastroenterology and Hepatology (ÖGGH) was founded by Wolfgang Petritsch at the 28th Annual Meeting of the ÖGGH in Vienna in 1994. The Chair of the Working Group is usually elected for 4 years (two 2-year periods) at the Annual Meeting of the ÖGGH. The Chair's responsibilities include establishing the main objectives of the Working Group, coordinating the annual meetings and representing the Working Group on an international level. She/he should be the driving force within the Working Group. Since its founding, the Working Group has grown continuously, now comprising more than 50 members representing at least 25 different hospitals in all of the nine Austrian federal states. At least nine of these centers have experience in performing clinical studies. Nevertheless, an even broader interest in the management of IBD is sought to achieve a minimal standard of care nationwide.

In chronological order, Wolfgang Petritsch, Harald Vogelsang and Herbert Tilg have led the Austrian IBD Working Group. In October 2006, Walter Reinisch took office as the current Chair of the Working Group.

The Working Group Chairs, past and present, describe how they came to be involved in IBD:



Wolfgang Petritsch, 1994–1997

- When I saw my first Crohn patient shortly after I started working at the University Department of Internal Medicine in Graz in 1979, I immediately realized how little we knew about the disease and how few treatment options there were. At first some people were surprised that I could get myself involved in something that was so rare, but soon the number of patients started to increase and then literally exploded in the last 10 years. Today, we see 1400 patients in our outpatient IBD service.

The biggest challenge for me is the usually early onset of disease and the danger of social disadvantage and invalidity at a young age.



Harald Vogelsang, 1997-2001

- When I was a resident in gastroenterology at Vienna General Hospital starting in 1983, my mentor Herbert Lochs sparked off major innovations in the care of patients with inflammatory bowel diseases.

- Together we supervised the growth of a small outpatient clinic whose patients were all personally known to us to one of the largest outpatient IBD clinics in Europe with more than 3 000 pa-

tients. We took part in clinical multicenter trials starting in the 1980s. My primary goal is individual care of these patients at the highest scientific level. All scientific rigor notwithstanding, close cooperation with all the other members of the working group in a friendly atmosphere has always been important to me.



Herbert Tilg, 2001–2006

- I began my research career two decades ago in the area of cytokines. At that time the two key proinflammatory cytokines interleukin-1 and tumour necrosis factor alpha (TNF) had been identified. By the time treatments based on cytokine antagonism (with interleukin-10 and later anti-TNF antibody) proceeded to clinical trials, my interest in patients with IBD had grown and I had the strong feeling that I had finally found a place where basic science and clinical medicine go hand in hand. It is the challenging combination of doing basic science and seeing patients with IBD that continues to fire my enthusiasm.





Walter Reinisch, 2006–2010

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(walter.reinisch@meduniwien.ac.at) – From my first experience in treating patients with IBD, I was deeply moved by those young patients afflicted with a lifelong, debilitating disease, which is largely taboo for patients, doctors and the health care system. IBDs pose underestimated medical problems due to the lack of adequate structures for patient management, although they can be expected to have a major economic impact on health care in the 21st century. Assuming an overall an-

nual prevalence of IBD of at least 20/100,000, the peak of first presentation in the 3rd decade, and a mean duration of disease of 40 years, incidences of 0.75% can be expected. Based on the facts that IBD patients tend to be diagnosed at a younger age, that the incidence of CD is increasing, and that life expectancy in general is increasing and may well increase for IBD patients in particular due to the advent of more efficacious drugs, it is likely that the incidence rate of IBD will break the 1.0% barrier. The health care system is not prepared for this and its administrators do not listen. It will be one of my major aims for the next four years as Head of the Austrian IBD Working Group to raise awareness of IBD on the part of the public and the responsible authorities to guarantee early diagnosis of IBD, which with a median delay of 3.1 years is still not the case, as well as to assure our patients of early and high quality management.



Peter Knoflach

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as senior IBD expert, substantially influenced the prosperity of the Working Group by his valuable experience and comprehensive knowledge in the field. He is also the local organizer of the yearly meetings of the group.

- My interest in IBD began in 1975 when I started working in what was then called the Colitis Outpatient Clinic at Vienna General Hospital. Today, in accordance with the international trend, we see considerably more patients with Crohn's disease. In the course of my scientific work in the 1980s, I was in

on the beginning of the immunological "revolution" in the understanding of IBD and it is gratifying that patients can now benefit from the immunological treatments that have in the meanwhile been developed. I hope for further major developments, until we can ultimately speak of a cure for these diseases.

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Objectives of the Working Group

- To encourage and deepen interest in IBD within the ÖGGH and on the part of the medical community and the general public.
- 2. To hold consensus conferences to define standards in diagnosis and treatment of IBD and to make them available to the medical community at large, with the intention of improving and unifying standards in Austria.
- 3. To conceive and conduct clinically relevant multicenter studies on IBD in Austria.
- 4. To encourage discussion, cooperation and exchange of experience through regular meetings of interested parties.
- 5. To create IBD competence centers.
- 6. To raise awareness on IBD in the public and the medical community.
- To provide a link between the Austrian IBD self-help group (ÖMCCV) and the medical community.
- 8. To communicate with the industry the need and profiles of new medications and diagnostic procedures.
- 9. To establish a political lobby for IBD.

The joint IBD Working Group so far has been directly responsible for:

Publications

Consensus conferences * Therapie des Mb. Crohn (Treatment of Crohn's disease). Forum Dr. Med. 1995;14:42-48 * Therapie der Colitis ulcerosa (Treatment of ulcerative colitis). Österreichische Ärztezeitung 1997;4:35-39 * Diagnostik bei CED (Diagnosis of IBD). Acta Med Austriaca 1998;25:37-43 * Diagnostik und Therapie von CED im Adoleszentenalter (Diagnosis and treatment of IBD in adolescents). Z Gastroenterol 2000;38:791-4 * Diagnostik und Therapie der Zöliakie bei Adoleszenten und Erwachsenen (Di-

agnosis and treatment of celiac disease in adolescents and adults).

Z Gastroenterol 2002;40:I-VII



* Medikamentöse Rezidivprophylaxe bei Colitis ulcerosa (Pharmaceutical prevention of relapse in ulcerative colitis). *Österreichische Ärztezeitung* 2003;1:40-41

* Immunosuppressive therapy for inflammatory bowel disease.

Z Gastroenterologie 2004;42:1033-45 * Infliximab in the treatment of Crohn's disease – a practical approach.

Z Gastroenterologie 2004;42:1256-63

* Aminosalicytes and steroids in the treatment of chronic inflammatory bowel disease. *Z Gastroenterologie* 2006;44:525-538

* Endoskopie bei CED (Endoscopy in IBD) *Z. Gastroenterologie* 2006;44:1183-1192

Other Publications

based on the acitivites of the group

Gasche C, Waldhoer T, Feichtenschlager T, Male C, Mayer A, Mittermaier C, Petritsch W. Austrian Inflammatory Bowel Disease Group. Prediction of response to iron sucrose in inflammatory bowel disease-associated anemia.

Am J Gastroenterol 2001;96:2382-87

Wenzl H, Reinisch W, Jahnel J, Stockenhuber F, Tilg H, Kirchgatterer A, Petritsch W. Austrian Infliximab Experience in Crohn's Disease: A nation-wide cooperative study with long term follow-up. *Eur J Gastronterol Hepatol* 2004;16:767-73

Oefferlbauer-Ernst A, Miehsler W, Eckmullner O, Travis S, Waldhoer T, Dejaco C, Gangl A, Vogelsang H, Reinisch W. Impact of interobserver disagreement on phenotype-genotype associations in Crohn's disease.

Inflamm Bowel Dis. 2007;13:156-163

In preparation

Teml A, Schwab M, Hommes D, Almer S, Lukas M, Feichtenschlager T, Florin T, Seiderer J, Petritsch W, Bokemeyer B, Kreisel W, Herrlinger KR, Knoflach P,Bonaz B, Klugmann T, Herfarth H, Pedarnig N Reinisch W.

A systematic survey evaluating 6-thioguanine-related hepatoxicity in patients with inflammatory bowel disease.

Ongoing

H. Wenzl et al.

Azathioprine cessation trial in Crohn's disease.

Meetings

Annual meeting of the IBD Working Group. Traditionally it takes place in the week after Easter on the Attersee in Upper Austria and is organized by P. Knoflach together with the chair of the IBD Working Group. Because of the particular focus of the Working Group, participation has so far been limited to specialists in IBD, but this limitation may be liberalized in the future.

Activities

Effects triggered

by activities of the Working Group: * Continuing specific education, e.g. five symposia in Pichlarn on immunosuppression and monoclonal antibodies in IBD.

* Numerous physician-patient meetings throughout Austria.

* Close cooperation with the ÖMCCV, an advocacy group for patients with ulcerative colitis and Crohn's disease.

* A major awareness campaign began in 2006 featuring press conferences, an IBD Day and round-table discussions. A survey to determine awareness in the general public of IBD revealed that less than 7% of the population has any awareness of IBD. Furthermore, studies have found that the interval from first symptoms to diagnosis of IBD is 3.1 years in Austria; this should be improved with increasing awareness on the parts of physicians and the general public.

* Close cooperation with the pharmaceutical industry, which has provided logistic and financial support for:

The Working Group's annual meetings
Symposia

– Symposia

 An annual prize for scientific work on IBD.

In this context, the Working Group is especially indebted to Merck, AESCA, Ferring, Abbott, UCB, Otsuka and Emonta for their corporate support.

* Development of the Inflammatory Bowel Disease Information System (IBDIS): IB-DIS was the product of a collaboration between the Austrian IBD Working Group and UNIDATA GEODESIGN initiated by Walter Reinisch in 1999. IBDIS represents a catalogue of standardized and validated variables embedded in a web-based data capture application, ready to be used for the registration, administration and scientific analysis of data from patients with IBD. IBDIS is already being applied in national and international registers and surveys, such as those on 6-thioguanin or infliximab.

* The Austrian IBD Working Group was a founding member of ECCO, which was officially established on March 24, 2001, in Vienna. ECCO in turn is an associate member of UEGF, United European Gastroenterology Federation, and the current Chair of the Austrian Working Group, Walter Reinisch, is also a member of the Scientific Committees of both ECCO and the UEGF.

Future aims

* To continue to pursue our primary goals and to improve our means of achieving them.

* Continuation of the awareness program, including the creation and placement of TV spots.

* Expansion of the IBDIS network throughout Europe.

* To assure, through provision of appropriate information, that new treatment options continue to be available in Austria to all patients when and as indicated, and without limitations.

* Nationwide care of IBD patients complying with defined minimal standards.

* Diagnostic software for an online IBD check to improve the surveillance competence of physicians in general practice and aid them in early detection and diagnosis of IBD.

* An IBD School, modeled after the ECCO School, to be held early in 2008.

* The establishment of an Autrian IBD Biobank.

* Preservation of the exceptionally cooperative and congenial atmosphere within the Austrian IBD Working Group. ■



Dr Simon Travis in Oxford

Dr Simon Travis is a member of ECCO's Scientific Committee.

Together with Professor Eduard F. Stange he has been responsible for organising the work with the ECCO consensus on Crohn's Disease and ulcerative colitis. He has written two articles in ECCO News about these Consensi that are going to be republished in the magazine during 2007.

S imon Travis is a Consultant Gastroenterologist and Clinical Director of Gastroenterology and Endoscopy at the John Radcliffe Hospital in Oxford.

It is the main teaching hospital for Oxford University. It was named after John Radcliffe, (1652–1714), a physician and polymath whose legacy funded the original Radcliffe Infirmary in Oxford in 1770.

Not from Oxford

The hospital is situated on a hill in Headington on the outskirts of Oxford.

Some of the patient's rooms in the gastroenterology ward have an astonishing view over the town and its famous landmark buildings.

Dr Travis enthusiastically points them out and describes them in meticulous detail, which makes us assume that he is an Oxford man himself.

- Not at all, is his answer.

– I was born in Devon, and later I went to Winchester College. They told me that I had no chance of going to Oxford or Cambridge to read medicine, so I went to London instead.

Diversity gives strength

So there's some irony in the fact that Dr Travis today has this high position in the University town.

He studied medicine at St Thomas' Hospital in London.

– I loved medicine immediately, he recalls.

– It struck a chord between the science involved, and the personal contact, which has never left me.

At Winchester College the science students had to continue learning about



Today I think that the strength of any unit lies in its diversity.

non-scientific subjects, such as literature, history of art and humanities. Something Dr Travis thinks was to their advantage later in life.

– I took an interest in ceramics, had a special interest in glazes and the history of ceramics. I need a diversional interest to science.

– Today I think that the strength of any unit lies in its diversity.

Started in intensive care

When Simon Travis finished at St Thomas', he knew what he *didn't* want to do – among those paths were for example psychiatry and gynaecology.

– I was strongly considering becoming a surgeon. The reason was that I liked to do things with my hands and make decisions. I wanted to be a medically orientated surgeon – I wanted to be able to use my head and think.

At medical school, he was House Physician to the Dean of medical school, Brian Creamer and Richard Thompson (later Sir Richard, the Queen's physician).

 Both of them were gastroenterologists. But I still didn't think of gastroenterology as my first choice of specialty.

To gain some more experience Simon Travis went for a job in the intensive care unit at St Thomas'.

It was a hard job – 120 hours per week
and it gave me a lot of experience.

Commando course

Simon Travis reveals that the Royal Navy had already paid for his medical school training, and he had had to take a leave of absence in order to work in the intensive care unit. It was a calculated risk – he wasn't sure that he would get the job at the time he had to take the leave.

But now he wanted to fulfil his commitment to the Royal Navy. The year was 1982 and he joined a ship.

- It was just after the Falklands war, and I spent six months sailing round in what appeared to be ever decreasing circles in the South Atlantic.

Coming back by way of the West Indies, he decided to do Royal Marine Training – he did the Commando course.

The Royal Marines training is the toughest basic infantry training programme of any NATO combat group. It is also the only Service in which officers – including doctors – and recruits are trained at the same place, and undergo the same physical tests.

Arctic research

This led to a new experience for Dr Travis.
− I had to do the same course as the





John Radcliffe Hospital in Oxford, UK.

Marines and I failed – and it was the first time in my life that I'd failed anything apart form a school test – and it was an education!

He continues by explaining that he believes that every person sets their own horizons.

The training pushed me to the limit
 but it also taught me that you impose
 your own limits and you can go *beyond* these limits. I went back and did it again.

For three and a half years, Dr Travis was a Commando Medical Officer.

- During this period I spent seven months in the Arctic. While I was there I researched frostbite and peripheral temperatures during Arctic warfare training, when the ambient temperature was down to minus 40 degrees centigrade.

 I wired myself and volunteers every time we went out on exercise for 3–4 days.
 We were living in snow holes or bivouacs and cold injury was a constant threat. I like to think that my research contributed to the decision to issue new boots and new socks to the Royal Marines.

From Cardiology to Gastroenterology

Leaving the Royal Marines behind him, Dr Travis then came back to hospital medicine.

 I went back to St Thomas' again. I had to decide what to specialise in, and I thought cardiology was interesting, so I started to train as a cardiologist.

The second year on the training rotation took him back to St Thomas' again – with his former bosses.

- My second year turned out to be in gastroenterology, so I thought that the writing was on the wall, so I decided to become a gastroenterologist!

He continues to explain it's a decision he never has regretted.

- Gastroenterology is endlessly fascinating. It's the interface between evidence based medicine and surgery demanding knowledge, practical skills and manual dexterity. It provides the stimulation of managing acute emergencies and the satisfaction of navigating patients through chronic illness, such as the relapses and remissions of IBD.

– It's the relationship you have with patients over a long period of time – and with colleagues of diverse disciplines – which makes ones working life so enjoyable, he summons.

Senior Registrar

In 1987 Dr Travis decided that he needed formal research training. He was offered a Junior Research Fellowship at Linacre College in Oxford with Derek Jewell.

The subject of his research was the effect of cytokines and inflammatory mediators on colonic epithelial function. This was a struggle until the "eureka moment" was when he found the influence of platelet activating factor on epithelial ion transport.

 That's how I got my DPhil – which is the Oxford equivalent of the Cambridge PhD, he explains.

After this, Dr Travis stayed in Oxford as a Senior Registrar where he worked on predictive factors in severe ulcerative colitis.

– From this work the Oxford predictive index was developed, he continues.

High altitude

During this period Dr Travis also developed an interest in gut physiology and carbohydrate absorption – which allowed him to combine academic *and* recreational interests.

- The carbohydrate absorption tests could be used on expeditions of high altitude to measure gut function. And that meant I could go climbing!

So in 1992 Dr Travis joined an expedition to Mount Everest – in winter!

- We didn't get to the top, due to a jet stream. It almost wiped out the climbers on South Col. (*The high camp before the summit, located at 26 000 feet, or 7 920 meters, editors note*)

- But I managed to get research samples that showed that carbohydrate absorption decreased above 5 000 meters by over 20%.

Plymouth

After two years as a Senior Registrar, Dr Travis became aware that a Consultant Gastroenterologist position had come up in Plymouth. He went for the post, and became Consultant there in 1994. He stayed for seven years.

 In Plymouth I did some clinical research and clinical trials, but no scientific research. My main purpose was clinical practice for my patients.

At the hospital there were a total of two Gastroenterologists, serving a population of 440 000.

We suffered a lot from the reorganisation of the National Health Service that took place at that time and it was wearing.
 But I still managed to organise a high altitude research expedition to Bolivia.

In 2001 a new Gastroenterology post, with a special interest in IBD, was established in Oxford.

- I applied for it, and was lucky to get it!



Gastroenterology is endlessly fascinating. It's the interface between evidence based medicine and surgery demanding knowledge, practical skills and manual dexterity.

ECC0

Dr Travis is still very happy to have this position.

 It's been immensely stimulating and enjoyable, he says and continues to explain why:

- Outstanding colleagues, superb interaction with surgeons, radiologists and pathologists. Hugely talented students and trainees. And it's all supported by a world class laboratory service.

On his return to Oxford, Dr Travis became a Fellow of Linacre College at the University of Oxford. He regards this as a great privilege, since it is a community of academics from diverse disciplines, mostly unrelated to medicine.

- I also became chairman of the IBD section of British Society of Gastroenterology, which led to the UK guidelines. Through that, I became involved in ECCO and with Eduard Stange. We started to work on the ECCO Consensus, first on Crohn's disease and now on ulcerative colitis.

Support from colleagues

He thinks that working with the Consensi has been very interesting and rewarding.

 It took us across different languages, different cultures and gave us an insight into the workings and the challenges met by colleagues in different countries. It also gave an insight into the European Union.

- The most rewarding aspect was the support of colleagues across Europe, because they believed it was more important to have a common voice than follow the furrow ploughed by influential individuals.

But Dr Travis has of course been deeply involved in other projects.

– I have done clinical trials on novel therapies for UC and Crohn's, he continues.

 This research led to the realisation of the need to validate the activity indices and quantify the interobserver variation in endoscopic scoring.

Clinicians important role

The subject leads him in on his general view on research, which he states with the utmost conviction:

- It is one of my core beliefs that the clinicians caring for patients today have an important role – more important than ever before – in refining the questions that science has to answer.

- This is because clinicians formulate the question that matter to patients. It's all too easy to be bamboozled by the complexity of cell-signalling genetics, or the other extraordinary advances in the un-



Dr Simon Travis in conversation with one of his patients.

derstanding of the pathophysiology of the disease. It's only clinicians that can anchor the science to patients.

Strength of the unit

John Radcliffe Hospital serves a population of 620 000, and there are only four Gastroenterologists, with another two in a small hospital in Banbury nearby.

- It's only possible to do this because we have strong academic links with Honorary Consultants, Dr Travis explains, and because we have long been supported by excellent overseas Research Fellows. Since 2006 we have three positions for Senior Clinical Fellows in Gastroenterology, which offer excellent experience and training for 12 months in Oxford as well as meeting the needs of the service.

 I have a strong belief in diversity and hybrid vigour. These are very important components for the strength of the unit.

Dr Travis reveals that they are in the process of appointing the first Sydney Truelove-Professor in Gastroenterology in Oxford, after the retirement of Derek Jewell who held a personal chair.

Extraordinary support

Dr Travis has been married for 23 years and has two children. He speaks of his family with great affection.

 My wife Pamela has been of immeasurable value, he says.

There is much travelling on Dr Travis' agenda, and he regrets that he has to spend so much time away from a lovely home in the Cotswolds.

He has a passion for trees and is planting an arboretum with magnolias, eucalypts and willows among other exotica that flourish in the alkaline soil.

– I have two delightful daughters: Clementine who is seventeen and Cressida who is thirteen – neither of whom show the slightest inclination to go into medicine, but are all the better company for it.



Inflammatory Bowel Diseases 2008

3rd Congress of ECCO - the European Crohn's and Colitis Organization

In collaboration with GETAID – Groupe d'Etude Thérapeutique des Affections Inflammatoires du Tube Digestif

Cité – Centre de Congrés Lyon, France • February 28 – March 1, 2008

Dear Colleagues,

It is a pleasure to announce the forthcoming 3rd Congress of the European Crohn's and Colitis Organisation (ECCO) that will take place in Lyon (France) from the 28th of February to the 1st of March 2008.

The prospect for the 2008 Congress in Lyon looks very attractive. This is to the result of the hard work done by our Scientific and Educational Committees, bringing up new ideas for lectures, symposia and debates, while always bearing in mind a holistic approach to the disease and the patient.

The programme will follow a similar format to Innsbruck, with one of ECCO's main aims that each of the subjects is approached in a translational way by both a basic scientist and a clinician. In addition, one whole morning will be devoted to LIVE-endoscopy demonstrations. There will be also oral- and poster presentations of accepted abstracts. ECCO Research Fellowships and Grants will be awarded and announced after the Innsbruck Congress. In addition, the 6th Advanced Course and the IBD Nurses meeting will take place, as well as events in conjunction with EFCCA that address the needs and concerns of the patients.

ECCO is rapidly developing and consolidating progress. The ECCO Congress is one of the corner stones where all those with an interest in IBD can meet, present and discuss the rapid advances in the knowledge of both pathogenesis and therapy. Care is taken to facilitate this interaction in order to provide the best care for the patients.

Our website, **www.ecco-ibd.eu** will be kept updated with information regarding the 3rd ECCO Congress.

ECCO looks forward to meeting you again in Lyon in 2008.

MIQUEL A. GASSULL President of the European Crohn's and Colitis Organisation JEAN-FRÉDÉRIC COLOMBEL President-elect of the European Crohn's and Colitis Organisation



Optimising biological therapy – practical considerations, current practice and future prospects

Workshop 1. Starting biological therapy, Prague 5th and 6th December 2006

Aims of the workshop series:

• To conduct a series of interactive meetings based on clinical cases which provide practical guidance and review the evidence to support use of biological therapy in Crohn's disease and UC.

• To create a set of slides and lecture notes from each meeting which can be used as an ECCO resource.

Major discussion points were as follows:

• There are still too few data to support many clinical decisions, especially concerning newer anti-TNF biological therapies. Data from the certolizumab and adalimumab development programmes may close some of these information gaps. The challenge then is to address differences in access to therapy, because national guidance or reimbursement policies often lag behind clinical evidence.

• Many of the clinical questions and answers relating to starting biological therapy in Crohn's disease translate to Ulcerative Colitis although data are still limited.

• Early treatment with biological therapy for selected patients can reasonably be expected to deliver a better outcome. Clinical information and molecular markers (genetic, serologic, ...) on which patients to select and whether early treatment alters outcomes that matter to patients (hospitalisation, surgery) are needed.

• Contraindications to biological therapy can usefully be recalled by the *STOIC* acronym adopted by Subrata Ghosh (Sepsis, TB, Optic neuritis (demyelination), Infusion reaction (hypersensitivity), Cancer).

• Patients with a history of cancer or dysplasia in need of biological therapy should be assessed on a case by case basis.

• Response to biological therapy can be maximised by:

- * An induction regimen of two or more doses before maintenance treatment.
- * Concomitant treatment with an immunomodulator for 6 months to reduce antibody formation.

* Early treatment for those with severe disease (such as extensive Crohn's disease, or disease in multiple sites, younger patients, presence of complications such as fistula at initial diagnosis).

• Surgery should be considered alongside the use of biological therapy and not left as a last resort. Patients should be included in discussions about whether surgery or biological therapy is the most appropriate treatment choice, having had benefits and risks of each option explained. This is particularly pertinent to young women or women of child bearing potential where data indicate that pelvic surgery impairs fecundity. They require special counselling around their treatment choices.

• Patients should be re-assessed regularly as part of a defined treatment plan. A second opinion or further specialist advice should be sought for primary nonresponders or secondary failures to biological therapy. • There was much discussion about whether "top down" therapy was appropriate and if so, how would you identify a suitable patient. Daan Hommes remarked "only safety concerns (and cost) generally prevent people from adopting a "top down" approach to treatment. If you adopt "top down" you may be over-treating a minority of those patients you select, but if you adopt "step up" you will be under-treating the majority". Boris Vucelic reminded the panel that "top down" is not recommended in the ECCO consensus guidelines and that we need more data to support this approach.

The meeting slides and notes will be available in early 2007. The next meeting on continuing biological therapy will be in Stockholm 11th and 12th April

This meeting series is supported by an unrestricted educational grant from UCB SA.

Chairs:

Severine Vermeire, MD, PhD. University Hospital Gasthuisberg, Leuven, Belgium Milan Lukas, MD, PhD, General Faculty Hospital, Prague, Czech Republic

Participants:

Walter Reinisch (Austria), Simon Travis (UK), Willem Bemelman (Netherlands), Yehuda Chowers (Israel), Daan Hommes (Netherlands), Janneke Van der Woude (Netherlands), Pia



Munkholm (Denmark), Bjorn Moum (Norway), Zuzana Serclova (Czech Republic), Julian Panes (Spain), Fernando Magro (Portugal), Milos Gregus (Slovakia), Boris Vucelic (Croatia), Peter Lakatos (Hungary), Edyta Zagorowicz (Poland), Sandro Ardizzone (Italy).

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The issues and questions relating to starting biological therapy were facilitated through case presentations as follow:

Complex Crohn's Disease Newly Diagnosed Crohn's Disease Chronic refractory Ulcerative Colitis Severe Ulcerative Colitis Yehuda Chowers, Tel Hashomer, Israel Pia Munkholm, Copenhagen, Denmark Walter Reinisch, Vienna, Austria Julian Panes, Barcelona, Spain



Inception cohort-epidemiology in ECCO

n 2001 I joined ECCO as a national representative of the Danish Society of Gastroenterology and as bridging to EC-IBD, European Collaborative study on Inflammatory Bowel Disease. In EC-IBD we were 12 countries and 22 centres from all over Europe that united in 1989 in Rotterdam under the leadership of professor Shiva Shivananda. The aim of the meeting was to promote epidemiology throughout Europe via inception cohorts in defined areas to verify if the hypothesis of a North-South gradient was real. Supported by a grant from the European committee the inception cohort from 1991-1993 was a reality altogether 2201 IBD patients, 1379 were diagnosed as UC (including proctitis), 706 as CD, and 116 as indeterminate, throughout Europe. The overall incidence per 100,000 at ages 15-64 years (standardised for age and sex) of UC was 10.4 (95% confidence interval (95% CI) 7.6 to 13.1) and that of CD was 5.6 (95% CI 2.8 to 8.3). When we applied the standardized international diagnostic criteria we were able to find a 40% higher incidence in North Europe of UC vs 80% higher of CD, i.e. for UC, rate ratio (RR) = 1.4 (95% CI 1.2 to 1.5)) and for CD, RR = 1.8 (95% CI 1.5 to 2.1). Although significant difference in incidence between North and South was revealed the differences were smaller than expected.

In 1995 professor Reinhold Stockbrügger in Maastricht took over the leadership and via two grants from the European committee (1995 and 1998) a 10 year follow-up until 2003 was conducted. Phenotype-genotype, cancer, mortality, disease course, pregnancy, communication and health cost and consumption, in all 7 working groups, were established. The Leuven group, Professor Severine Vermeire and Professor Poul Rutgeerts joined us to introduce analysis of various candidate genes and polymorphism. 4 Phd's came out of our efforts:

PhD's originating from the EC-IBD cohort 1995–2007:

Ingrid van der Eijk, MSoc, PhD, The Netherlands: The role of quality of care in health-related quality of life in patients with IBD.

Lene Riis, MD, PhD, Denmark: Genotype and phenotype, pregnancy and disease course. A European cohort study of IBD patients. www.dccd-ibd.dk

Frank Wolters, MD, PhD, The Netherlands: Disease outcome of inflammatory bowel disease patients: general outline of a Europe-wide population-based 10-year clinical follow-up study.

Ole Hoie, MD, PhD, Norway: Ulcerative colitis disease course and mortality in a European-wide population-based cohort 10 years after diagnosis.

Health cost and consumption was analysed by Selwyn Odes in Israel and probability of intestinal cancer by Epinondas Tsianos, Kostas Katsanos in Greece. In addition to that more than 38 publications have been published in peer reviewed magazines.

EC-IBD has from 1 October been incorporated in ECCO which all members in EC-IBD has agreed to. Pia Munkholm took over the leadership and the database with each EC-IBD centres data moved to Copenhagen.

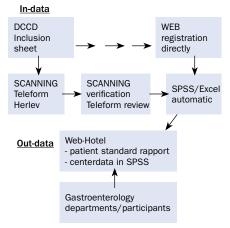
Future aspects of epidemiology within Europe are being planned. 4 new trials is undertaken in the old cohort 1991–2003: Health consumption(Odes S, Israel), Natural disease course (O'Morain C, Ireland), Quality of Life (Mous B, Bernklev T, Norway), Transition of medical disease course (Vermeire S, Wolthers F) and Steroid use (Langholz E, Riis L).

A new inception cohort from 2008 to clarify if environmental factors and candidate genes are causing the East-West gradient, lower incidence in East Europe compared to West Europe is being planned. In Russia Professor Elena Belouvrusa, in Czeque republic, Professor Milan Lukas and Professor Boris Vucelic in Croatia are representing eastern part of Europe with relatively low incidences of IBD. By the steadily increasing westernising lifestyle the incidence of IBD could change fast in the near future. Via DCCD, Danish Crohn Colitis Database, the web-based solution combined with the possibility of scanning of datasheets of inception cohort trials makes an example of a more feasible solution of inclusion of inception cohorts throughout Europe and their follow-up, see figure.



EC-IBD inception cohort areas from 1991– 1993 followed till 2003.

Danish Crohn Colitis Database – DCCD 2007



With the increasing incidence reported since 1962 to 2005, in a PhD, from Denmark as well as identical reports from other parts of Europe the search for an environmental factor in the western lifestyle is a tempting hypothesis to be explored in coming years.

Ida Vind, MD, ph.d. Genetic, serological, and environmental factors in a Danish inception cohort of patients with inflammatory bowel disease, 2003–2005. *www.danmedbull.dk*

The 2 old inception cohorts from DCCD and EC-IBD has now been secured on a large server at MUNK-IT, a company known for high safety procedures accepted and certified by EMEA and the Data Registry and Agency in Denmark and Europe.



Congress	Date	Venue	Further information
International/Europe			
European Society of Coloproctology (ESCP)	26-29th September 2007	Malta	www.escp.eu.com
15th UEGW	27-31th of October, 2007	Paris, France	www.uegw.org
40th ESPGHAN	9-12nd of May, 2007	Barcelona, Spain	www.espghan2007.org
ASNEMGE 4th Summer School of Gastroenterology	21-24th of June, 2007	Prague, Czech Republic	www.asnegmge.org
IOIBD	19-22nd of April, 2007	Avila, Spain	www.ioibd.org
Falk 158 colorectal carcinogenesis	23-24th of March, 2007	Sevilla, Spain	www.falkfoundation.com
Falk 159 IBD 2007	4-5th of May, 2007	Istambul, Turkey	www.falkfoundation.com
Falk 160 Pathogenesis & Clinical Practice	15-16th of June, 2007	Portoroz, Croatia	www.falkfoundation.com
Falk 160-162 Gastro-Congress	10-14th of October, 2007	Dresden, Germany	www.falkfoundation.com
EFFCA General Assembly Meeting	21-25th of March 2007	Sevilla, Spain	MickeLindholm@pp.inet.fi
3rd International Congress on Gastrointestinal Oncology	14-16th of June, 2007	Hersonissos, Greece	www.gi-oncology2007.conferences.gr
Czech Republic & Slovakia			
Slovakian and Czech IBD Meeting	27th of April,2007	Nitra, SK	jelena.vavrova@vfn.cz kmmanagement@post.sk
Spring IBD Meeting	11th of May, 2007	Prague	jelena.vavrova@vfn.cz
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
Germany			
DGVS - 62. Jahrestagung der Deutschen Gesellschaft für Verdauung und Stoffwechselkrankheiten	12-15th of September, 2007	Bochum	www.dgvs.de
Greece			
6th National Congress for IBD	1-3rd of June 2007	Heraklion	kouroum@med.uoc.gr, info@eligast.gr
France			
Journées Francophones de Pathologie Digestive	17-21st of March, 2007	Lyon	www.snfge.org
Hungary			
49th Annual Meeting of Hungarian Society of Gastroenterology	1-6th of June, 2007	Tihany	www.gastroent.hu
Italy			
XIII Congresso Nazionale delle Malattie Digestive	5-9th May, 2007	Palermo	www.fimad.net
IG-IBD Congress	15-16th of December 2006	Rome	maurizio.vecchi@unimi.it
IBD Congress and Course	14-15th of December	Milan	maurizio.vecchi@unimi.it
Latvia			
III Latvian Gastroenterology Congress	10th of November, 2007	Riga	http://www.kongresu-nams.lv
Lithuania			
ECCO Group Conference	13th of December 2006	Kaunas	gedikiud@takas.lt
The Netherlands			
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
Serbia-Montenegro			
National Gastroenterology Congress	25-28th of March, 2007	Belgrade	njegica@Eunet.yu
Sweden			
Swedish Gastroenterology Congress	2-4th of May, 2007	Uppsala	gastrodagarna@congrex.se
Switzerland			
8th Berner IBD Symposium	29th of March, 2007	Bern	Frank.Seibold@insel.ch
United Kingdom			
British Society of Gastroenterology	26-29th of March, 2007	Glasgow	www.bsg.org.uk
	10.100 (1.10007	Manahaatan	
Association of Surgeons of GB & Ireland	16-18th of April,2007	Manchester	www.asbgi.org.uk





Rod Mitchell, the EFCCA Chairman, introduces readers to EFCCA and reports on their early October 2006 Annual Meeting in Paris at the time of the French IBD Patients association AFA 1st National IBD – MICI Day

bout 17 years ago in Germany and facilitated by the Falk Foundation a group of like-minded national IBD patient representatives from Crohn's and colitis patient organisations met together for the first time in a knowledge exchange. From those early exploratory discussions and influenced by the European ideal of strength through cooperation the "umbrella" association to be known as EFCCA was born in the town of Freiburg in October 1990 and subsequently registered under Belgian law. Controlled by an elected Board and Executive/Management Committee, the Chairman, Secretary and Treasurer currently undertake most of the daily work. Recent changes to the EFCCA structure and governance are outlined in the report from the EFCCA Paris annual meeting shown below. These will assist EFC-CA's European level activities and work with and for the member associations as it continues to grow in membership and to face the challenges of the rapidly changing healthcare environment of the 21st century and the increasing numbers of IBD patients Europe-wide presently estimated at > 1.2m (CD 500,000 + UC 700,000). Contact details and further information for EFCCA including its aims and objectives can be found on the website at www.efcca.org where contact info is also provided for the 23 national Crohn's and colitis patient organisations.

Europe fights against IBD

Breaking the silence... Briser le silence was part of the challenge taken up by EFCCA delegates and the members of Association Francois Aupetit – AFA in early October when they were together in Paris at the time of EFCCA's 16th Conference and General Assembly and AFA's First National IBD–MICI Day to raise awareness of the difficulties of living with IBD.

EFCCA patient delegates from 20 countries also decided to raise the tempo across Europe in the fight against IBD. Early in the week representatives of EFC-CA joined an evening discussion group at the Hospital St Antoine and after their annual meetings joined more than 300 AFA members, families and citizens on Saturday 7 October at AFA's major event at the Cite des Sciences at Paris La Villette for those interested in learning more about Crohn's and colitis and the fight against IBD.

EFCCA also took decisions at its own General Assembly to "modernise" its governance and management structure, held discussions about the possibility of greater co-operation with ECCO and moved further forward with the new EFCCA project to establish an EFCCA European IBD Research Foundation. An EFCCA Friends of IBD will also be launched to assist. In addition delegates heard about the positive work of the EFCCA Youth Group, the review of the Travelling with IBD Info from which country summaries will become available via the EFCCA website, and finally the First EFCCA Pan European IBD Patient Study out of which a Poster was accepted for the UEGW Berlin Congress. Also for the first time an end of day satellite session was provided about Clinical trials. The IBD patient delegates found the session very helpful and sought answers to many questions.

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In talking together in Paris La Villette Rod Mitchell, the long serving chair of EFCCA, and Patrick Riaudet, the President of AFA, pledged to raise the tempo on their respective plans to see how more resources can be discovered and used for IBD Research to find cause and cure, while at the same time importantly they undertook to work to "break the silence and taboo" surrounding these often debilitating life long conditions and to help those peoples diagnosed with Crohn's and colitis to cope with their everyday lives as very many really do still feel socially isolated through their often life-long illness.



ROD MITCHELL Chairman EFCCA



Young ECCO (YECCO) Report

Since the first YECCO meeting (Berlin October 2006), our group of young investigators enthusiastically started with its activities. In this issue of ECCO News we give a short overview of our progress.

Membership

At the start up of YECCO, our group consisted of 33 members who all had attended the ECCO course on IBD in Amsterdam 2006. In the meanwhile, however, our group expanded and, at the moment, has 65 members out of 21 different European countries and Israel. We hope and expect to recruit many more young investigators in the near future.

Attendants to any of the ECCO courses on IBD (from Prague 2003 to Innsbruck 2007) have recently received an electronic invitation to join the group, but any other young investigator with a special interest in IBD is more than welcome to become a YECCO member.

Everyone who wishes to join YECCO can ask for an application form by sending an email to *youngecco@yahoo.com*

The YECCO Board will soon send a letter to all ECCO National representatives with the request to invite all young people enrolled in the National IBD Groups to contact YECCO. Of course, we would also like to propose the ECCO News readers, to encourage the young investigators at their centres to become part of Young ECCO.



Website

To deal with the growing number of members and the necessity of a good communication of our activities, decisions and discussions, YECCO would like to set up a website or webpage. For this purpose, we recently asked ECCO permission to create a YECCO subpage on the existing ECCO website. The ECCO Governing Board will discuss our request during the meeting in Innsbruck. We hope to start our webpage immediately after this congress.

Research Projects

One of our major goals is to start scientific multi-centre projects, conducted by our young investigators. During the weeks following our first meeting, we agreed on a standard way of writing project proposals and we worked out a feasibility report. A feasibility report is a small document that each member is invited to fill out and send back to the project promoter within 15 days. It describes whether a centre can participate in a project, how many patients/samples can be included by this centre and if there are any adjustments to improve the protocol itself.

Last month we collected already 8 scientific study proposals, which will soon be sent to the Scientific Committee of ECCO. The SciCom will decide which project can be started and will be funded. In the next issue of ECCO News we hope to give you more information on their decisions.

Do you want a personal subscription to ECCO NEWS?



The aim of ECCO NEWS is to reach all doctors in Europe with an interest in IBD. ECCO NEWS is an important part of the European Crohn and Colitis Organisation's ambition to create a European standard of IBD care and to promote knowledge and research in the field of IBD. The newsletter is financed through advertisements and distributed free of charge. If you are yet not on the mailing list you can have a personal paper copy sent to your postal address 4 times a year. Just send an email to **ecco@mediahuset.se** stating your postal address. The information you give will not be used for any other purpose than distributing ECCO NEWS.

> TOM ÖRESLAND Editor ECCO News



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