

A story of success:
Feeding science, digesting knowledge.



European
Crohn's and Colitis
Organisation

10 year ECCO Anniversary Book





Acknowledgement

ECCO would like to thank all the contributors who have made this Anniversary Book so successful. Especially Renzo Caprilli, Miquel Gassull, Geert D'Haens, the editors of the book, and the ECCO Office team who all excelled in condensing all our fondest memories into this book.

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Foreword

*Tell me and I forget
Teach me and I will learn
Involve me and I will remember*

Confucius

The words of Confucius reflect a lot of what ECCO stands for. In our mission, to improve research, education and collaboration in the area of Inflammatory Bowel Diseases (IBD), we have tried for the last ten years to involve all of those who were willing to truly contribute, from students to experts, from nurses to scientists. This involvement resulted in an authentic approach to advance our organisation towards the success that we are able to celebrate today. But please, don't think that we didn't make mistakes along the way! How do you manage to get 31 countries and different cultures around one table? How do you avoid politics and monumental egos to influence your roadmap? When do you decide to jump into the unknown with your own medical journal? Calling an auditorium full of people and a great party your "First ECCO Congress", are you kidding?

Well friends, looking back these were times that were scary but a lot of fun! We have grown into a European family, supporting each other in the "ECCO Spirit" and united around one goal: The welfare of IBD patients. We want to share the tales, the excitement, the sad moments and the unpaved road ahead. Please join us today and be inspired by our 10 year ECCO Anniversary Book, a collection of wonderful stories and great pictures capturing this history of the first pioneering years to where we are today.

If the history of ECCO is a twenty chapter book, we have only just finished our first chapter. Please help us write our next!

On behalf of the ECCO Governing Board,

Daan Hommes

Preface: Why ECCO?

Sometimes, time flies. That has certainly been the case for ECCO.

More than ten years ago, at an IBD meeting in Padua, Italy, Geert D'Haens talked to Renzo Caprilli about the recently founded Belgian IBD Research Group and its efforts to launch the “top-down trial” in the Benelux. At the same time, two similar IBD groups had been active in Italy (North and Central-South) for some years, with regular meetings and interesting scientific initiatives. Would it not be a good idea to exchange ideas, discuss studies among the groups and – why not – cooperate on certain scientific projects? Two other groups in Europe immediately caught our attention: The GETECCU in Spain, led at the time by Miquel Gassull, and the French GETAID, which already had a history with an impressive research and publication track under the initiative of Robert Modigliani.

We felt compelled to launch a European initiative for IBD at a time that the European political entity was evolving to bring the whole of Europe closer together. Our idea was to create an IBD voice in Europe. We decided to approach GETECCU and GETAID, to contact a few key people in other European countries (initially W. Reinisch in Austria, Y. Chowers in Israel, B. Vucelić in Croatia and C. Hawkey in the UK) and decided to organise a first (rather informal) meeting during UEGW Rome 1999.

We felt a bit uneasy at this meeting, not really knowing in which direction this would lead us. Later on, we spent two years contacting more key people from other countries, whom we met at

UEGW Brussels 2000 and UEGW Amsterdam 2001. We also convinced a few pharmaceutical partners to embark on the journey. Moreover, we decided to meet for the “official start” of the European IBD Organisation in Vienna, at Hotel Regina, that very Saturday in 2001, where ECCO was born. The organisation did not bear the name ECCO yet (it actually took several more months and internet voting to decide on the eventual name), but there was a beginning of a structure, a common goal and above all the friendship and determination to make this project succeed. These characteristics, in addition to enthusiasm and transparency, have come to be known as the “ECCO Spirit”.

Very soon thereafter we decided that the first area where our efforts would be of value was in IBD education. It was surprising to all of us that, in an era of evidence-based medicine, daily clinical practice differed so much among the European member states. Hence, we met in Mallorca to organise the first ECCO Students' Course, kindly organised by Milan Lukáš in Prague.

The success of the ECCO Course was enormous and gave us the courage and strength for further development. We now look back with great satisfaction on how ECCO is thriving. Thanks to Italian inspiration and Flemish perspiration ECCO has become the place to be, for research and education in IBD and a vista of opportunities for all doctors and professionals who have the great enthusiasm and passion for their field that we ourselves have always had.

Renzo Caprilli, Geert D'Haens, Miquel Gassull

How the dream became reality:

The early days and the first activities



Geert D'Haens and Renzo Caprilli in Padua, Italy, 1999

The early days of ECCO go back to January 1999 when Geert D'Haens and I met in Padua at the University Hospital during a meeting organised by the Padua IBD Group. Sitting at the cafeteria of the hospital, Geert and I agreed that there were a number of scientific groups in Europe very actively engaged in IBD. We therefore discussed the idea of organising a meeting of all the European IBD groups, just to inform each other about current projects and explore possible cooperation between the groups.

Therefore, taking advantage of the opportunities presented by the 7th UEGW taking place in Rome that year and me being a member of the Organising Committee, we organised the first meeting of the European IBD National Groups. That was in Rome, during UEGW, on November 15, 1999. We contacted and invited some leaders of other countries: Jean-Frédéric Colombel and Marc Lémann of the French GETAID, Miquel Gassull of the Spanish GETECCU, Boris Vucelić from Croatia and Walter Reinisch from Austria.



The flyer of UEGW Rome 1999 and the programme of the first meeting of the European IBD National Groups

The meeting was successful as representatives of the national groups of seven European countries attended (Belgium, Denmark, France, Italy, Norway, Spain, The Netherlands). Each representative presented the organisation and the activities of their group. A mailing list was drawn up of all those interested in our initiative and I was nominated as temporary Secretary. The meeting closed with a cocktail kindly offered by Giuliani.

The second meeting of the European IBD National Groups was held in Brussels on November 26, 2000 again during UEGW. Four new groups joined (Austria, Czech Republic, Finland and Greece) and two prospective cooperative studies were discussed: "The early detection of PSC in IBD" and "IBD and pregnancy". Taking into consideration the great interest aroused by the two meetings, Geert and I explored the possibility of founding a European IBD Group Association (or Society). There was a very fruitful discussion on this matter soon after the meeting in Brussels and the idea of the foundation of the European Association of National IBD Study Groups was very well accepted and approved by those in attendance (W. Reinisch, J-F. Colombel, I. A. Mouzas, Y. Chowers, among others).

Geert D'Haens and Harald Vogelsang were therefore appointed to organise a meeting in Vienna, entirely dedicated to the foundation.

The birth of ECCO

The foundation of the European Crohn's and Colitis Organisation (ECCO) became official in Vienna at Hotel Regina on March 24, 2001.



External view of Hotel Regina, Vienna



Meeting room of Hotel Regina, Vienna:
"Birthplace" of ECCO

The name of ECCO was actually defined by ballot some months later.



The first logo of ECCO (homemade)

Representatives of 14 European countries attended this important meeting: Austria (W. Reinisch, H. Vogelsang), Belgium (G. D'Haens), Croatia (M. Premuzic), Czech Republic (M. Lukáš), France (J-F. Colombel), Germany (P. Bayer), Greece (I. A. Mouzas, A. Pallins), Ireland (B. Ryan), Israel (Y. Chowers), Italy (R. Caprilli, R. de Franchis), Lithuania (L. Kupcisinkas), Spain (T. Obrador), The Netherlands (M. Russell), United Kingdom (C. Hawkey).

I opened the Vienna meeting and presented the aims of the foundation of the organisation, in particular the need to have a European voice in the field of IBD. Hereby, I would like to report the conclusions of my introduction speech in Vienna:

"Dear friends, I have briefly summarised the early days of our group and the efforts we have done, without any financial support, for drawing the group up. I sincerely hope we can continue to work together enthusiastically and friendly also in the future. Transparency should be our motto. Only in this way the Society will be able to reach the appointed objectives and become the official voice of IBD in Europe."

During the Vienna meeting the objectives, the members and the Governing Board of ECCO were defined:

Objectives:

- Promote, sponsor and steer European international research in the field of IBD,
- Enhance European research quality in the field of IBD,
- Organise education in the field of IBD,
- Develop cooperation with UEGF and with patient organisations,
- Establish consensus and challenge dogmas in the field of IBD (evidence-based),
- Have a political voice in Europe and serve as reference point for the pharmaceutical industry.

Members:

Members of the organisation are not individuals, but European National IBD Study Groups.

Governing Board:

The Governing Board consisted of eight members elected from the representatives of the National Groups.

The first ECCO Governing Board:

President:

Renzo Caprilli (2 years)

Secretary:

Geert D'Haens (3 years)

Treasurer:

Walter Reinisch (4 years)

Vice-President:

Miquel Gassull (3 years)

Chairmen of the Scientific

Review Board:

Jean-Frédéric Colombel (4 years)

Boris Vucelić (4 years)

Assistant for Protocol Writing:

Chris Hawkey (2 years)

Yehuda Chowers (2 years)

Development of ECCO

ECCO was born. Then we needed to establish the rules of the organisation and to expand the visibility of ECCO throughout Europe.

It was in July 2001, that Geert D'Haens, Walter Reinisch and I met in my office in Rome at Policlinico Umberto I° and drafted the first version of the ECCO Statutes. We spent a full day of very fruitful discussions and established the basis of ECCO's future.

The statutes focused, above all, on three aspects:

- Federal characteristics of the organisation,
- Scientific and educational activities,
- Collaboration with other organisations.

It rapidly became evident that in order to increase the visibility of ECCO in Europe, it was essential to become a member of the United European Gastroenterology Federation (UEGF). Hence, I explored this possibility with Alberto Montori, who was Chairman of the UEGF Executive Council at that time. With his intercession I had the opportunity to present the objectives and structure of ECCO at the meeting of the UEGF Council in Amsterdam in 2001, after which ECCO became an Associated Member of UEGF. This acquisition was a milestone in the history of ECCO, because as an Associated Member, we had the right to hold two strategic positions within UEGF – one in the Executive Council (myself) and another in the Scientific Committee (G. D'Haens). In this way we had a chance to have a voice in the politics of UEGF and to contribute to the scientific programme of UEGW. According to the so-called "Ponza

Formula", we also started to take part in the revenues of UEGW.

Side note and quote of the decade, 2001 from Chris Hawkey (UK) to Simon Travis when taking over as chair of the IBD section in the UK. Simon Travis: *"What on earth is ECCO? I've never heard of it."* Chris Hawkey: *"Oh, a European IBD interest group. Don't worry; it won't take up much of your time!"*

Another important step of the early days of ECCO was the first meeting of the ECCO Governing Board, which was held in Palma de Mallorca in 2002, organised by Miquel Gassull and Antoni Obrador.

In this meeting we planned the main activities of ECCO for the future:

- Relationships with National Representatives,
- Relationships with other organisations (UEGF, EFCCA, IOIBD, EC-IBD),
- Invitation of the pharmaceutical companies interested in IBD to become ECCO Corporate Members,
- Establishment of the ECCO website,
- Instituting the Intensive Course for Junior Gastroenterologists, to be held in a different country each year,
- The course was restricted to two or three young doctors from each ECCO Country Member allowing for a maximum of 40 participants in total. The courses were greatly appreciated and contributed very much to the improvement of knowledge in IBD throughout Europe.

Following this policy, we rapidly succeeded in obtaining even greater space and visibility for IBD at UEGW in terms of symposia, round tables and scientific communications. The visibility of ECCO started to increase and ECCO rapidly became popular within Europe and even beyond. As a result, some changes in the structure were necessary.



Front of the second Medical Clinic, University of Rome "La Sapienza", Policlinico Umberto I, Rome

Therefore, in 2004, it was agreed to set up three new committees: Liaison Committee, Scientific Committee (SciCom) and Educational Committee (EduCom). The functions of President-Elect and Past-President were also instituted.

The ship was built, the crew and the skipper were ready, but we needed the fuel to sail. We therefore decided to invite pharmaceutical

companies interested in IBD, to become corporate ECCO Country Member. Giuliani was the first firm that joined ECCO followed by Centocor, Falk, Ferring and Protein Design Laboratories (PDL). The fuel was found and the ship finally left the port.

Let me say that when we started to work on the project of developing a European organisation of IBD, my belief was that we would be successful. We as European people all shared a common cultural background, mostly coming from the Roman and Mediterranean culture. I will never forget the nice conversation that Miquel Gassull (Spain), Jean-Frédéric Colombel (France), Boris Vucelić (Croatia) and I (Italy) had in Dubrovnik during lunchtime at one of the first meetings of ECCO. I was very much impressed to see how deep their knowledge of Roman history was. I definitively realised then, that this common cultural background would represent the main basis of the success of ECCO.

Thanks to the members of the Governing Boards and the various Committees who invested a great deal of time and enthusiasm in the growth of the organisation, and thanks to the progressive increase of the importance of IBD in the field of gastroenterology, ECCO is now the largest IBD organisation in the world.

I can say that our dream has become reality.

Renzo Caprilli

The first European IBD Courses: Tough and intensive

Although ECCO now organises many successful educational activities, the oldest is known as the “ECCO Course”.

ECCO has tried, since 2003, to immerse young and promising gastroenterologists into the complex world of the pathogenesis, diagnosis and management of IBD.

The idea of organising an “ECCO Course” arose at an early meeting of some members of the ECCO Governing Board and Committees, during an early spring weekend in Mallorca, hosted by the late Antoni Obrador. The aim was to discuss the possible activities that ECCO could organise outside regular meetings, which at that time only consisted of the annual UEGW. The initial discussion mainly involved proposals for studies or clinical trials to be organised by ECCO. In Mallorca, several ideas were put forward by those present. Among them, I remember clearly Renzo Caprilli, Geert D’Haens, Pierre Michetti, Boris Vucelić (who was the Chairman of the Educational Committee), Milan Lukáš, Tom Øresland, Walter Reinisch and Chris Hawkey. I apologise if I forget any others. It was during this meeting that Antoni Obrador and myself suggested the possibility of organising a course aimed at young gastroenterologists interested in IBD. Our proposal was based on the experience that the Spanish Group for the Study of IBD (GETECCU) had gained by organising courses such as this, for final year gastroenterology residents. We illustrated our proposal with the results and experience GETECCU had gained over eight or nine years. The value of such a course was immediately

recognised by the meeting and it was agreed to organise the first “ECCO Course on IBD for Junior Gastroenterologists” in Prague, May 1-3, 2003. Milan Lukáš was appointed as local organiser and Boris Vucelić and Pierre Michetti, as Chairman and member of the Educational Committee, as well as myself, as a member of the ECCO Governing Board, were appointed as the course “directors”.

An essential component for this type of course was that the audience should be no larger than 40 students. The final programme was agreed by the “directors” during DDW in San Francisco at 6:30 in the morning, seated outside the Convention Centre. In short, the content included lectures ranging from basic science to diagnosis and management, combined with discussion of clinical cases. In addition, four 30 minutes seminars were planned each day. All students had to attend all of them. So this meant that the tutor had to repeat the same seminar four times. Activities would start at 8:30 and close at 18:30, with a 20 minute break each morning and afternoon, and 45 minutes for lunch. The rest of the day was free (probably to lie in bed exhausted). The duration of the course should be two days.

Geert D’Haens always remembers that I said that the course “had to be tough and intensive”.

It was indeed planned this way, both for the students and faculty!

The first course took place in the magnificent historical buildings of Charles University in the city of Prague. The organisation by Milan Lukáš was outstanding. 32 students from 18 countries were accepted, proposed by National Representatives of the ECCO Country Members. A few were already well-trained and although young (Séverine Vermeire was among them) – were outstanding.

Austria	Ireland
Belgium	Israel
Croatia	Lithuania
Czech Republic	Poland
Denmark	Portugal
France	Slovakia
Germany	Slovenia
Greece	Spain
Italy	Switzerland

Countries of the participants of the 1st ECCO IBD Course, Prague, 2003

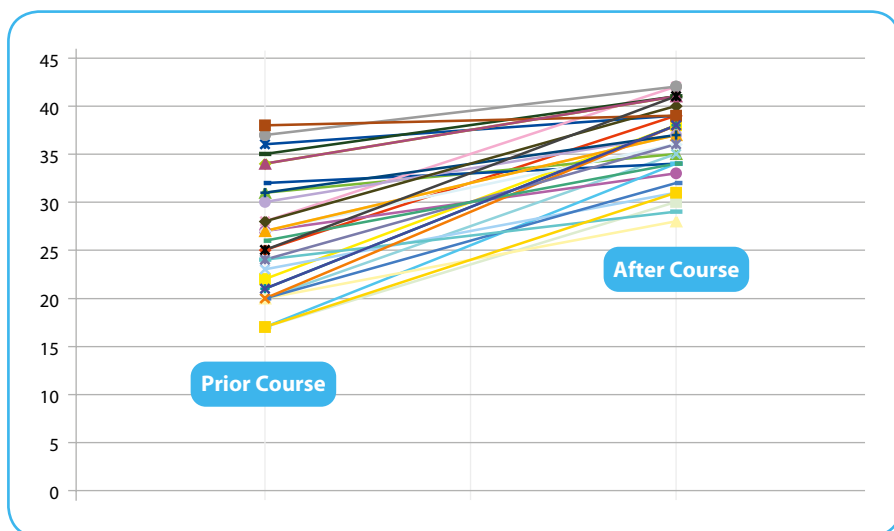
It ran smoothly and was very interactive, favoured by the low student/faculty ratio (less than two), the long day together, the coffee-breaks, lunch and an evening at the "Magic Lantern".

It is worth mentioning the outcome of this first course. The median number of correct answers of the 42 questions of the knowledge test before the course was 25 (range 12 to 38). At the end, the number of right answers was 36 (range 28 to 41). One person improved from 25 to 41 and another from 38 to 39 (guess who?). The mean percentage of the increment in knowledge was 25%. At the end of the course, an anonymous "satisfaction test" was completed by the students (novel stuff, in those days!). Although some comments on the organisation, set-up and lack of handouts were received, the content, lecturers, interaction and friendly atmosphere, were very positively rated.

From the start we were concerned about educational quality. The course started with a knowledge test, which was then repeated at the end, to evaluate its effectiveness in improving the knowledge of the students. I always remember the afternoon before the first course. We wanted to check the accuracy of the knowledge test, so all the faculty (R. Caprilli, Y. Chowes, P. Michetti, G. D'Haens, S. Schreiber, B. Vucelić, T. Øresland, P. Munkholm, R. de Franchis, W. Reinisch) did the test and afterwards had to reach agreement on the answers. It was an exemplary experience, although not easy, but it was a lot of fun.

The first words of welcome to the course were that "we could promise nothing from this course, except hard work".





Absolute number of right answers to the ECCO IBD Course knowledge test; n=32

The three crucial questions in our opinion were:

- Which is in your opinion the adequacy of the rhythm of the course?
(score 0 – 10): mean 5.94 (range 2 to 9)
- How much did the course meet your expectations?
(score 0 – 10): mean score 8.72 (range 7 to 10)
- According to your experience, would you recommend this course to your fellow colleagues?
(score 0 – 10): mean score 9.61 (range 7.5 to 10)

We concluded that the ECCO Course was worthwhile and although the course was “tough and intensive” (note the lowest scores!), it was well regarded by the participants as GETECCU had experienced. Changes to the structure and content were the consequence of the feedback from the students.

The ECCO Course, or the ECCO School as Boris Vucelić, by then Chairman of the Educational Committee liked to call it, became the forefront activity of ECCO, first as a unique activity (Prague, Dubrovnik, Poltu Quatu) and afterwards as part of the ECCO Congress: Amsterdam, Innsbruck,

Lyon, Hamburg, Prague and now Dublin. The ECCO Course has been a culture medium for young clinician-scientists interested in IBD and became the seed of Y-ECCO.

The European Crohn’s and Colitis Organisation, now with 31 Country Members in 2011, has become well known and respected. Although ECCO is highly regarded for its annual congress, research and education through guidelines and symposia, it is the ECCO Course that stands as one of the most important and popular events in our organisation.

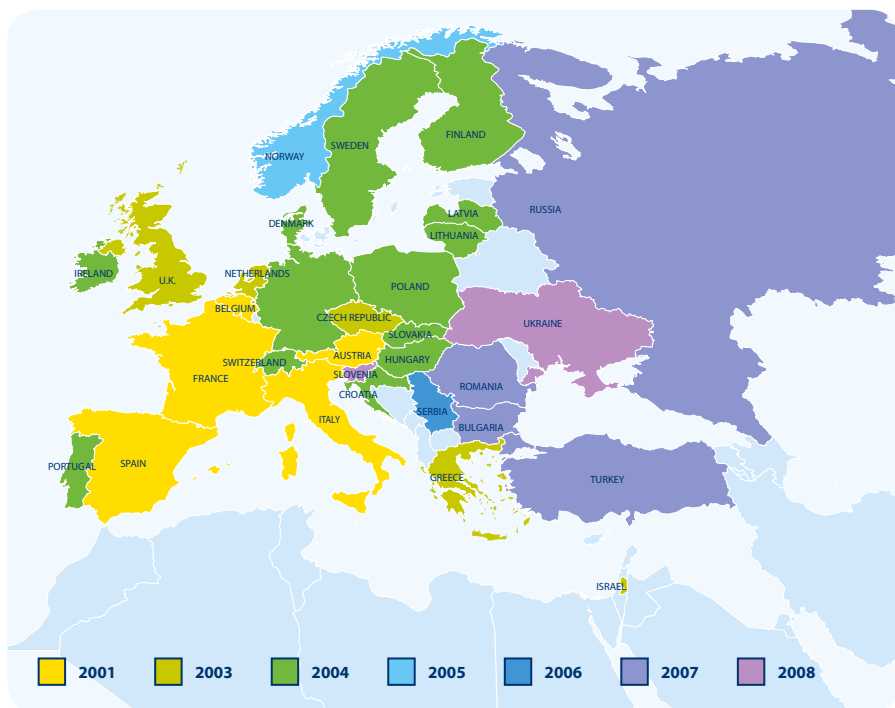
Miquel Gassull

ECCO's growth and expansion

The original idea of ECCO was to gather together existing national study groups throughout Europe.

However, we rapidly bumped into several problems. Some countries had multiple groups (such as Italy), other countries had "regional"

groups, while some had no IBD group at all and finally, some (such as the UK and Germany), had a flourishing IBD section as part of their existing national society. The first Governing Board was convinced, however, that all nations in Europe ultimately should join and therefore individuals were approached to facilitate this process.



ECCO's growth in country membership

Year after year new countries officially joined ECCO and presented their activities at the annual General Assembly during UEGW. ECCO started as federation of nations, for national groups committed to IBD and this was a strength, because it diluted individual egos. People were committed to the organisation and its principles.

From 2001 to 2006, each Sunday evening at UEGW became a celebration of welcome. To underscore the "festive aspect" receptions were held after these meetings in Rome, Brussels and Amsterdam. Later on we organised ECCO dinners for ECCO National Representatives and ECCO Sponsors. These were truly wonderful evenings. Looking back at the minutes, I find that Hungary joined in 2004, presented by Peter Lakatos. This process also created some problems, since active membership meant payment of the national membership fee and not all groups could (or would!) meet this requirement. Fortunately, industrial partners were willing to help them out if needed.

After 2006, it became clear that national membership alone was too weak as a basis for the further growth of ECCO.

After discussion with other organisations (including EASL) we realised that individual membership would lead to more personal involvement of the members. In spite of the many difficulties faced by this new approach (including potential financial shortcomings), individual membership was launched in 2008. Hours were spent on discussions on how to make this membership attractive and affordable. In addition, the founders of ECCO were concerned to maintain the concept of "national groups" as a federal component of the organisation.

Let me cite (verbatim!) from the minutes of the Governing Board meeting from July 2006:

"Several proposals are made as to how members should be accepted, from selective to very open. There is agreement that the threshold should be kept really low. The proposed fee is EUR 50 and EUR 25 if <35 years of age. Members who attend the Innsbruck Congress become member at reduced fee – Herbert to work out! Or can new members attend the Innsbruck meeting for free? Benefits to members: Access to website (member-only section), newsletter, reduced fee for the congress, attendance of activities restricted to members, inclusion in "Who is Who" (later potentially subscription to a journal). Then follows a discussion as to how National Representatives will be elected and what their duties/privileges will be. We have received criticism from a number of countries with regard to the democratic election procedures: Czech Republic, Finland, Germany, Slovakia, Portugal, Lithuania, Poland. We will send out a letter to these countries to obtain information about their selection procedures (Geert to do). The proposal is to accept virtually all applications for individual members and to have the National Representatives selected by the national scientific group which we recognize as ECCO."

Looking back, I think the right decisions were made. An organisation such as ECCO cannot live without individual members; it needs its own journal and its own annual meeting. With increasing numbers of active members and congress participants, ECCO's growth has been beyond our expectations. ECCO has filled a gap in international scientific and educational "needs" for IBD both in Europe and around the world.

Geert D'Haens

Dealing with success:

The need for rules

ECCO has been a success story ever since its inception in early 1999 for several reasons.

The most important ones are the fast evolving field of IBD, the dedication and enthusiasm of the experts engaged in the various activities of ECCO and the real need for ECCO services in education and science throughout Europe.

The official foundation of ECCO was in 2001. The first ECCO Statutes at that time emphasised the promotion of European international research, uniformity in education in the field of IBD in Europe and cooperation with patients' organisations, as well as UEGF. The first statutes reflected the federal character of ECCO, with a relatively simple organisational structure consisting of National IBD Research Groups with their representatives forming the General Assembly, a Governing Board and representatives of ECCO to UEGF. The legal seat of ECCO was the place of work of the General Secretary.

The activities of ECCO, among others, resulted in the organisation of the first "ECCO Advanced Course in IBD" in 2003 and the adoption of several scientific projects which required more complex organisational forms. Since the declared objectives of ECCO were the promotion of international research and education to foster equivalent high standards of IBD management in Europe, it was logical to embrace within ECCO

those IBD National Groups in countries without established research groups. Enthusiasm within ECCO had also led to a series of initiatives – from establishing a scientific committee to match the Education Committee, creating guidelines through a formal consensus process and establishing first ECCO Fellowships and then ECCO Grants and Travel Awards.

The first revision of ECCO Statutes in 2005 therefore defined the

- Representation of National IBD Groups through National Representatives,
- Establishment of the Education Committee and Scientific Committee (it was the idea of Daan Hommes to abbreviate the name of ECCO Committees to SciCom, EduCom and the like),
- Procedure for election of members of the Governing Board,
- Funding of ECCO by national groups and supporting pharmaceutical companies,
- Role and responsibility of the Past-President as Liaison Officer of ECCO
- Work on consensus guidelines (coordinators of these activities became members of the Education Committee).

The rapid growth of ECCO became critical in 2007 when it became imperative to have adequate administrative support to meet the needs of greatly expanded activities. That was realised by



Boris Vucelić's nomination for Honorary Member, 4th Congress of ECCO, Hamburg, 2009

the contract with the association and congress management company *vereint* in Vienna. Year 2007 was also the year when ECCO Educational Workshops were launched, to bring the ECCO Guidelines (first published in 2007) to a local or regional level through case discussions based on the consensus. In 2007 the revised statutes also recognised IBD specialist nurses as members of ECCO and established honorary members as a new category of membership. It was also the year that the Nurses' Course (N-ECCO Network Meeting) was launched and Young ECCO (Y-ECCO) was formalised. Last but not least, the new statutes better defined the role of the Council of National Representatives and Corporate Members.

Writing statutes for any organisation can be tedious, but it is a necessary task.

It is essential for transparency in the organisation and therefore to avoid (or at least minimise!) division. In a rapidly developing organisation it is even more important that statutes are updated frequently. This means thinking one or two years ahead: It takes time and imagination for evolving needs to be recognised, new statutes to be drafted, agreed by the Governing Board and then approved by the General Assembly. Get it wrong and the organisation does not have a structure fit for purpose. Enthusiasm then wanes amid confusion. Indeed, reflecting on the developing structure of ECCO, it might be likened to the development of political maturity: From a (benign!) autocracy, necessary at the start when those with vision make executive decisions, through a managed democracy to fully democratic and accountable procedures. Full democracy, with individual membership



Presentation of the new ECCO Structure by ECCO President Daan Hommes at the Extraordinary General Assembly, UEGW Barcelona 2010

and voting rights (for those “members in good standing” who had paid their dues!) replaced the federal structure. Nevertheless, the stage of managed democracy through the federal structure was an essential step, not least because it meant that there was country representation. People worked for the benefit of the organisation rather than for personal acclaim. Full democracy can be too big a step at the beginning, causing an organisation to lose direction.

Since 2007, ECCO has further developed and has now truly reached maturity with an impressive growth of individual membership, congress participants, growth of its own journal and corporate partnership. It has become the leading European authority in the field of IBD, responsible for the IBD programme at the UEGW. This did not happen by chance:

An early success was the recognition of ECCO by UEGF, with representation on the Scientific Committee. This transformed the IBD content of the scientific programme at UEGW (and, it is our belief!) the meeting as a whole. In addition, the number of stakeholders has greatly increased with epidemiologists, surgeons and paediatricians joining ECCO. The work on guidelines resulted in a number of consensus conferences requiring more dedicated organisational work in that area and more planning for the future. Nurses ECCO (N-ECCO) was charged with responsibility to optimise education for nurses in IBD by being actively involved in national IBD networks and in the development of standards of nursing IBD care. It therefore became obvious that new statutes have to be written and adopted, regulating the increasingly complex structure of ECCO.



Approval of revised ECCO Statutes at the Extraordinary General Assembly, UEGW Barcelona 2010

The third revision of statutes, adopted in 2010, reflected the complexity of the organisation, with major changes in the ECCO Structure. The first major change was the creation of the independent ECCO Office in Vienna, which has already proved to be a very efficient tool for the organisation and coordination of various ECCO activities. The new statutes clearly define the mission and objectives of ECCO, with an emphasis on the original objectives of ECCO as well as on transparency of its activities. The different categories of members, the admission process for each category, as well as the rights and responsibilities, are precisely defined. The transition from country membership to individual membership was recognised with the definition of country membership in substantive and geographical terms. The organisation of ECCO was re-structured, with the introduction of the Operational Board (OB)

and the Strategic Council (SC). The reason for these changes was the need to streamline the activities of numerous new stakeholders active in ECCO and to define the responsibilities and duties of each stakeholder.

It has become necessary to reach out to partners outside of Europe and establish closer relations with countries beyond European boundaries. To start with, the responsibilities of Education Officer and Scientific Officer were greatly expanded. Further, the newly formed Operational Board became responsible for merging all scientific and educational activities with their operational implications. As a result, all activities of EduCom, SciCom, EpiCom, ClinCom (Clinical Trials' Advisory Group), GuiCom, Y-ECCO, N-ECCO, P-ECCO (Paediatricians' ECCO) and S-ECCO (Surgeons' ECCO) are coordinated within the Operational Board under the supervision of the Governing Board. The OB

is chaired by the Secretary, Education Officer and Scientific Officer. Complementary to this is the Strategic Council, whose primary role is to deal with external affairs and relations within ECCO. The Strategic Council consists of National Representatives, Honorary Members, members of the Global Relations Committee and representatives of other stakeholders like UEGF, IOIBD and EFCCA. Its work is coordinated by the current President, Past-President and President-Elect of ECCO. Finally, the publications of ECCO, the Journal of Crohn's and Colitis (another great success of ECCO) and ECCO News, found their place in the new ECCO Statutes.

Readers will realise that the frequent changes of ECCO Statutes were not the commonplace consequence of problems within an organisation but, on the contrary, the reflection of numerous positive changes that occurred in a very short period of time. ECCO developed so quickly that we had to act quickly in order to legalise the existence of new forms of life that blossomed in the organisation. We are all therefore very proud of the success of ECCO, the organisation that has accomplished so much in just ten years of its existence. It will not stand still and will always look to the future.

Boris Vucelić

ECCO and science of IBD:

How SciCom was born

The idea of founding ECCO was introduced to me by Renzo Caprilli and Geert D'Haens. There was a feeling that something “had to be done” about realizing the enormous potential in the IBD field within Europe. The “what” and the “how” to do it were still unclear. How this was resolved is related in other sections of this book. People with an interest in IBD gathered under the ECCO umbrella and the diversity of approaches, ideas and cultures created the ECCO mosaic.

Science related to IBD was always a fundamental goal of ECCO.

It rapidly became apparent that it is impossible to discuss and plan scientific activity in the Governing Board. At that time, Renzo Caprilli suggested the creation of a scientific committee to form a body dedicated to this purpose. It was Daan Hommes who coined the abbreviation SciCom, creating a hallmark abbreviation for all ECCO Committees. In contrast to today's organised selection of SciCom Members, the first gathering of SciCom in 2004 was based on the enthusiasm of ECCO Members who had a strong interest in research and were ready to dedicate their activity to this goal. Daan Hommes was selected by the Governing Board as the first chair, and together with Walter Reinisch, Séverine Vermeire, Simon Travis and myself the first SciCom started to function. Meetings took place at the houses of members until formal offices and meeting venues were available. These first years of activity were a mix of hard work, enthusiasm and unashamed



Daan Hommes, Séverine Vermeire, Simon Travis, Daan's secretary Patrizia, Walter Reinisch and Yehuda Chowers at Simon's country house close to Oxford, 2005

fun. We had a blank sheet. Nothing was there and everything could be created: Fellowships, Grants, scientific programmes, collaborations, trials, new concepts to emphasise and Travel Awards. With this came the creation of the structure and regulations for future activity, since (perhaps conscious of our unelected position) transparency was the watchword



"Who is Who" in ECCO, old and new design



from the start. This was particularly important with the appraisal of Fellowship and then Grant applications and then with the reviewing of ECCO abstracts, always thinking of ways that the process could be improved and open to independent scrutiny.

Despite clear differences between SciCom Members (apart from the Caiparinha capacity), the first SciCom functioned harmoniously, united in a wish to create a truly transparent, pan-European effort to progress science related to IBD, to balance basic, translational and clinical projects and to lay a foundation for future scientific activities of ECCO. Driven by enthusiasm, SciCom got into everything at first, creating the first ECCO logo and the "Who is Who" in ECCO, initially published on paper. How long ago that seems!

Notice the change in **ECCO logos** (refer to page 131): The top was initially proposed by SciCom in 2005 and was replaced by the second in 2007, when the number of stars was felt to give insufficient importance to the rectum or its product. Simon Travis is delighted that the current logo at last recognises English and not US spelling of Organisation!

The **"Who is Who" in ECCO**, describing the names and resources of IBD specialists in all ECCO countries, was no self-congratulatory exercise. It defined ECCO at an individual level, identifying the leading names and IBD investigators in each country. This formed the basis of an initiative with PDLBioPharma. PDL was undertaking an ambitious trial of visilizumab, an anti-CD3 monoclonal antibody, in Acute Severe Colitis and agreement was

reached with SciCom to facilitate recruitment by giving each SciCom Member a sector of responsibility. SciCom Members then used regional conference calls to address questions about recruitment or safety, with the result that European recruitment far outstripped that in the United States. SciCom also created an opportunity for independent appraisal of drug development projects, very different to a standard Advisory Board, by contracting to a formal, written appraisal of plans before submission to regulatory agencies. SciCom also endeavoured to interact with the regulatory agencies (the European Medicines' Evaluation Agency, EMEA as then was), with myself and Simon Travis presenting to the Efficacy Working group of the Committee of Human Medicinal products at Canary Wharf. Despite proposing a structure for advice by IBD specialists independent of industry, it was clear that IBD barely broke the surface of their consciousness. Nevertheless, SciCom contributed substantially to the EMEA (now EMA) guidelines on clinical trial design in Ulcerative Colitis and Crohn's Disease.

ECCO Fellowships were an early SciCom initiative, designed to promote science and interaction between countries. Fellowships, created in 2005, enable young IBD trainees to work in another country on a project for a year. **ECCO Grants** were created in 2006 and are for research within the applicant's institution. These have proved particularly popular, with a Nature paper (by Sofia Buonocore from Oxford Nature 2010; 464:1371-5.) already coming from an ECCO Grant. Indeed, so popular were the Grants that SciCom made a mistake by awarding four, and not the two first sanctioned by the Governing Board. This set an (admirable!) precedent, so sometimes it is better to ask for forgiveness and for permission!

The **IBD Scientific Programmes of UEGW** have been driven by ECCO through the ECCO representative allied to an independent member of the UEGF Scientific Committee (G. D'Haens and W. Reinisch, followed by S. Vermeire and, more recently, myself) since 2003 (see the article by W. Reinisch for more information). Ideas and themes for the programme are discussed within SciCom and new speakers always sought. This has been the same for the **ECCO Congress**, initiated by Daan Hommes in Amsterdam and recounted elsewhere. Making a good programme needs imagination and interaction, with discussion often going on into the early hours of the morning: On one occasion in Leuven the SciCom meeting started at 22:00 and finished no one can recall when. It is just as well that discussions were below the radar of WikiLeaks! Nevertheless, the popularity of the programme at the ECCO Congress speaks for itself and the Organising Committee of the congress now has representation from SciCom, EduCom and local organisers.

EpiCom joined SciCom in 2007, when it was looking for a locus after the completion of the European Collaborative initiative on IBD (EC-IBD). EpiCom's story is told elsewhere in the book.

We made and learned from mistakes. Keen to promote European collaborative projects, ECCO supported a pan-European project on pregnancy in 2003. This required substantial investment by ECCO, but the duration exceeded the gestation period of several generations, because of lack of scrutiny of the infrastructure and statistical appraisal. As a consequence, SciCom developed a process for appraising ECCO projects to which it would lend its name. All's well that ends well, however, because the pregnancy project has

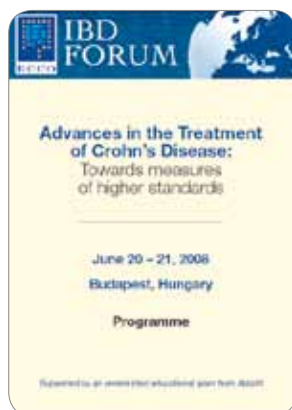


The ECCO Biological Workshop, London

now delivered (by caesarean section) – with an abstract at ECCO Congress in 2010 and a paper in the process of being submitted. Thanks, Aurora Bortoli and Pia Munkholm for being the obstetrician! Current ECCO projects are on the website.

So open was the landscape in the early years that SciCom contributed substantially to other initiatives that have now re-located within ECCO. These include the **ECCO Guidelines**, driven by Eduard Stange (see his article). Boundaries were poorly defined in those days and GuiCom, created after the first ECCO Consensus on Crohn's Disease, initially lodged with SciCom before moving under EduCom's wing. SciCom also used the guidelines to create case-based workshops when Lucid, a (very) newly formed company facilitating interaction between specialists and industry, asked what ECCO was doing to communicate the ECCO Guidelines at a local or regional level. Boris

Vucelić had the same idea within EduCom (see the article by Pierre Michetti) and created the formal and highly regarded ECCO Educational Workshops, initially led by Gert van Assche and now by Gerassimos Mantzaris and Rami Eliakim. Nevertheless, Lucid facilitated a series of four "ECCO Biological Workshops" in 2006, on cases based on the ECCO Guidelines, supported by UCB. The CD still exists! Another first – and a lesson learned – was the ECCO IBD Forum, developed by SciCom with Lucid in 2007. The lessons learned were two-fold: First the immense popularity around the world for ECCO initiatives (delegates came from 28 different countries for a highly interactive meeting) and second, the problems related to single company sponsorship. ECCO was exposed by appearing to sanction promotional activities if only a single company was involved. Consequently a rule was rightly made that ECCO activities would not have single sponsorship, even though this meant the end of a highly successful initiative.



Cover of the IBD Forum programme, 2008



IBD Forum Hungary 2008

Then there was the real science for SciCom and ECCO. Recognition that collaborative research was difficult to do well, potentially expensive and bad for ECCO if done badly, meant that this was delayed as other activities were developed. ECCO was, of course, a surrogate supporter of science through Fellowships and Grants. In 2008 and 2009, however, two new initiatives from SciCom started. One was the creation of **Pathogenesis Workshops**, designed to address a single question, with working groups performing a systematic review to be published and setting the goals for research to answer the question. The research would be funded by open application to grant-funding bodies, including ECCO for pilot work. I led the first workshop (on reasons for loss of response to anti-TNF therapy, now published in JCC) and

a new project is started each year. The second initiative addressed the need for independent advice on clinical trials, establishing the Clinical Trials' Advisory Group, ClinCom. Originally driven by Marc Lémann, it is now being established under the leadership of Geert D'Haens to provide advice and independent appraisal of scientific projects of ECCO Members.

Personally, I feel privileged to have participated in the pioneering activity of SciCom and to meet people who have become esteemed personal friends. It is truly exciting to see how this bud has developed and how new, talented and motivated members of SciCom are leading the way to future success.

Yehuda Chowers, Simon Travis

ECCO Congresses:

From Amsterdam to Dublin



Participants of the 5th Congress of ECCO, Prague, 2010

The annual ECCO Congress is definitively the crown of ECCO's achievements.

Few of us ever thought that our ECCO Congress would have such an explosive growth since the first congress in Amsterdam. What started just five years ago with a modest-scale meeting in Amsterdam, organised at the time by Daan Hommes has triggered a series of educational and scientific activities, resulting today in a top flight, well-attended

and outstanding scientific meeting. The ECCO Congress attracts more and more non-European physicians, nurses, clinical fellows, scientists and colleagues from as far afield as Asia, Australia, Canada, the United States and through the alphabet of countries to Zambia.

Reflecting on past congresses, what are the **ingredients** that make the ECCO Congress so successful?

When analysing a wonderful recipe, it is not that exotic ingredients are necessarily used, but the whole menu which appeals and invites you to taste. Careful choice of the best ingredients and the balance in how they are mixed makes a delicious meal. If, on top of that, the meal is consumed with good friends, accompanied by selected wines and a wonderful atmosphere, then that will make an evening memorable!

So it is with the ECCO Congress: Nicole and her team are the perfect hostesses and are always meticulously prepared. They have an eye for the smallest details, assist where they can and are the master-chefs in making all speakers, students, nurses, and physicians feel at home. I can tell you in all honesty that, if you feel the adrenaline as a speaker, then this is nothing compared to how Nicole and “the girls” feel during the three days that the meeting is running!

The excellent **wine** is served by the local organisers: They proposed and promoted their city to ECCO and now selected as the host city of the ECCO Congress, they defend it in all its aspects. The best use is made of the most beautiful locations, in castles, old colleges, at the sea and we have had parties in an old convent, as well as a student’s course on the beautiful island of Sardinia.

Let’s serve **the menu** then. The **first course** usually develops the appetite and is welcomed by those who are hungry: The young students who follow the IBD Advanced Course. This course is undoubtedly regarded as the best of its kind: Small-scale, to make it fully interactive, with very easy access for our leaders-of-tomorrow to meet and discuss with current experts in Europe. It is reassuring

to see that our future is secured with so many young IBD rising stars! Being myself one of the students of the very first IBD Course organised in Prague in 2003, I have to admit that I also made mistakes in my course exam (we blamed the teachers, of course, for not making their questions clear enough!). I was very pleased to be invited back the following year only to find out that it was to teach this time!

The **main course** is of course the ECCO Congress itself. Whereas generally speaking, a “buffet-style dinner” looks very appealing and overwhelming in choice, nothing can beat a nice dish, prepared for you by the Chef and served to you at your table with your friends. Believe me, this is so much better than finding your own selected sessions. For me, ECCO should always stick to this linear format of one programme, one room and no parallel sessions. This is, in fact, the most commonly cited feedback that ECCO has received all these years. People have suggestions on how to improve the meeting, but the one thing which does not need improvement (or put even stronger: which should never be changed!) is the absence of parallel sessions. Is there anything more annoying than having to choose between two sessions that you both wished to attend, so not hearing the expert’s opinion on a topic simply because you happened to be in the other room. It’s like choosing the salmon for the main course when turbot is on the plate next door.

I hope that those who organise the meetings after us will remember this, because the demand to cram in more is very tempting. The ECCO Congress follows this unique concept and is consequently distinct from other meetings, such as our large international



"Mister red-pants" Simon Travis and Janneke van der Woude, ECCO Interaction, 5th Congress of ECCO, Prague, 2010

European and American Gastro meetings. This is a good thing.

Finally, **dessert**: Something sweet to finish a delicious meal! I am a big dessert-fan! The dessert of the ECCO Congress must be the ECCO Party. But the word "party" became politically incorrect. It needed an Oxonian to rename the party "ECCO Interaction: Hearts and Minds". But in truth, this captures the "ECCO Spirit". No tedious congress reception this! The recurring theme (besides DJ Walter!) here is "Mister red-pants", and for those who do not understand what I mean: Come to Dublin and find out more!

Looking back at the menus that we have had in past years: We have had excellent overview talks, new guidelines, tandem talks (Miles, this is still one of my best experiences –



DJ Walter in action, ECCO Interaction, 5th Congress of ECCO, Prague, 2010



Séverine Vermeire and Miles Parkes, tandem talk "Genetics of IBD and Clinical Implications", 3rd Congress of ECCO, Lyon, 2008

many thanks!), challenging cases and original work. It is notable that the abstracts submitted have seen a tremendous growth and this year, more than 450 abstracts have been submitted! The rejection rates have been on the low side (10-15%) to enable people to participate, but as the numbers continue to increase, this may change slightly, if only to maintain or increase the quality of the meeting. We must not forget that this is a good thing for Europe and that will put us in a stronger position!

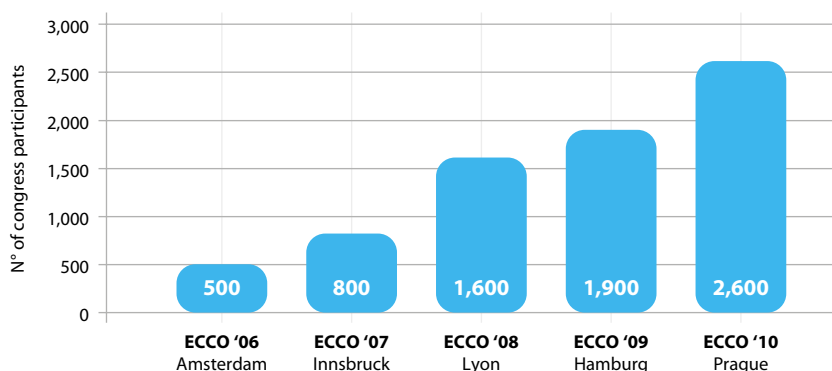
If I were a restaurant critic, I would reward ECCO with a Michelin star. I have always come

back from the ECCO meetings feeling fulfilled and very satisfied, but not stuffed – as you do from a good restaurant: You return to the restaurant and bring new friends.

The challenges for future ECCO Congresses, especially if they continue to grow in size, will be to keep the authenticity, the spirit of friendship and always to serve both good wine and dessert!

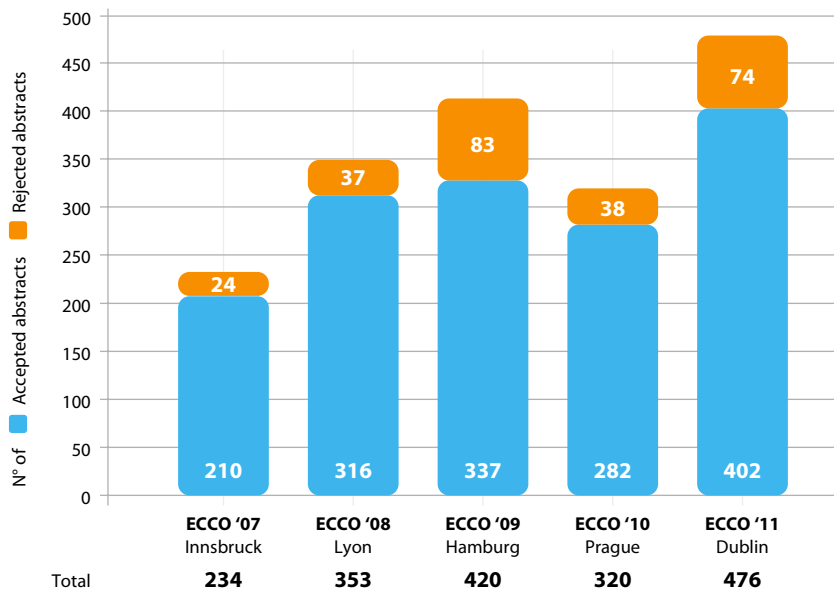
Séverine Vermeire

ECCO Congress participants

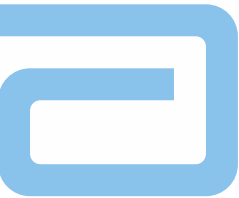


Participants at ECCO Congresses, 2006 – 2010

ECCO Abstract submissions



Abstract submissions at ECCO Congresses, 2007-2011



For patients with severe, active Crohn's disease who fail or are intolerant to conventional therapy,

With sustainable remission,
life goes on.¹



Before



After^{1,2}



And after



And after



And after



And after



And after

With sustained remission rates for at least 3 years, HUMIRA helps your patients with Crohn's disease live a more normal life.¹

References: 1. HUMIRA Summary of Product Characteristics, August 2010. 2. Data on file. Abbott Laboratories, North Chicago, IL.
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HUMIRA
adalimumab

Sustainable remission¹

Abbott
A Promise for Life

Prescribing Information

Humira (adalimumab) 40mg solution for injection in pre-filled pen or pre-filled syringe

Refer to Summary of Product Characteristics for full information.

Presentation: Each 0.8ml single dose pre-filled pen or pre-filled syringe contains 40mg of adalimumab.

Indications:

Rheumatoid arthritis (RA): Humira in combination with methotrexate is indicated for the treatment of moderate to severe, active RA in adult patients when the response to disease-modifying anti-rheumatic drugs (DMARDs) including methotrexate has been inadequate. Humira is also indicated for the treatment of severe, active and progressive RA in adults not previously treated with methotrexate. Humira can be given as monotherapy in case of intolerance to methotrexate or when continued treatment with methotrexate is inappropriate. Humira has been shown to reduce the rate of progression of joint damage as measured by X-ray and to improve physical function, when given in combination with methotrexate.

Polyarticular juvenile idiopathic arthritis (JIA): Humira in combination with methotrexate is indicated for the treatment of active JIA in adolescents aged 13 to 17 years who have had an inadequate response to one or more DMARDs. Humira can be given as monotherapy in case of intolerance to methotrexate or when continued treatment with methotrexate is inappropriate.

Psoriatic arthritis (PsA): Humira is indicated for the treatment of active and progressive PsA in adults when the response to previous disease-modifying anti-rheumatic drug therapy has been inadequate. Humira has been shown to reduce the rate of progression of peripheral joint damage as measured by X-ray in patients with polyarticular symmetrical subtypes of the disease and to improve physical function.

Ankylosing spondylitis (AS): Humira is indicated for the treatment of adults with severe active AS who have had an inadequate response to conventional therapy.

Crohn's disease (CD): Humira is indicated for treatment of severe, active CD, in patients who have not responded despite a full course of therapy with a corticosteroid and/or an immunosuppressant, or who are intolerant to or have medical contraindications for such therapies.

Psoriasis (Ps): Humira is indicated for the treatment of moderate to severe chronic plaque psoriasis in adult patients who failed to respond to or who have a contraindication to, or are intolerant to other systemic therapy including cyclosporine, methotrexate or PUVA.

Dosage and administration:

Humira should be initiated and supervised by specialist physicians experienced in the diagnosis and treatment of RA, JIA, PsA, AS, CD, or Ps. Patients treated with Humira should be given the special alert card. After proper training in injection technique, patients may self-inject with Humira if their physician determines that it is appropriate and with medical follow-up as necessary. During treatment with Humira, other concomitant therapies (e.g., corticosteroids and/or immunomodulatory agents) should be optimised. RA, JIA, PsA or AS: 40mg administered every other week as a single dose via subcutaneous injection. RA: In monotherapy some patients who experience a decrease in their response to Humira may benefit from an increase in dose intensity to 40mg every week. There may be a need for dose interruption, for instance before surgery or if a serious infection occurs. Available data suggest that reintroduction of Humira after discontinuation for 70 days or longer resulted in the same magnitudes of clinical response and similar safety profile as before dose interruption. For RA, JIA, PsA and AS, available data suggest that the clinical response is usually achieved within 12 weeks of treatment. Continued therapy should be carefully reconsidered in a patient not responding within this time period. JIA: The recommended dose of Humira for patients with JIA, aged 13 years and above is 40mg adalimumab administered every other week as a single dose via subcutaneous injection. CD: The recommended Humira induction dose regimen for adult patients with severe CD is 80mg at Week 0 followed by 40mg at Week 2. In case there is a need for a more rapid response to therapy, the regimen 160mg at Week 0 (dose can be administered as four injections in one day or as two injections per day for two consecutive days), 80mg at Week 2, can be used with the awareness that the risk for adverse events is higher during induction. After induction treatment, the recommended dose is 40mg every other week via subcutaneous injection. Alternatively, if a patient has stopped Humira and signs and symptoms of disease recur, Humira may be re-administered. There is little experience from re-administration after more than 8 weeks since the previous dose. During maintenance treatment, corticosteroids may be tapered in accordance with clinical practice guidelines. Some patients who experience decrease in their response may benefit from an increase in dose intensity to 40mg Humira every week. Some patients who have not responded by Week 4 may benefit from continued maintenance therapy through Week 12. Continued therapy should be carefully reconsidered in a patient not responding within this time period. Psoriasis: The recommended dose of Humira for adult patients is an initial dose of 80mg administered subcutaneously, followed by 40mg subcutaneously given every other week starting one week after the initial dose. Continued therapy beyond 16 weeks should be carefully reconsidered in a patient not responding within this time period.

Contraindications:

Active tuberculosis or other severe infections such as sepsis, and opportunistic infections; moderate to severe heart failure (NYHA class III/IV) and hypersensitivity to adalimumab or any of the excipients.

Precautions and Warnings:

Infections:

Patients taking TNF-blockers are more susceptible to serious infections. Impaired lung function may increase the risk for developing infections. Patients must therefore be monitored closely for infections, including tuberculosis, before, during and for 5 months after treatment with Humira. Treatment with Humira should not be initiated in patients with active, chronic or localized infections until infections are controlled. In patients who have been exposed to tuberculosis and patients who have travelled in areas of high risk of tuberculosis or endemic mycoses, such as histoplasmosis, coccidioidomycosis, or blastomycosis, the risk and benefits of treatment with Humira should be considered prior to initiating therapy (see *Opportunistic infections*). Patients who develop a new infection while undergoing treatment with Humira should be monitored closely and undergo a complete diagnostic evaluation. Administration of Humira should be discontinued if a patient develops a new serious infection or sepsis, and appropriate antimicrobial or antifungal therapy should be initiated until the infection is controlled. Physicians should exercise caution when considering the use of Humira in patients with a history of recurring infection and/or underlying conditions which may predispose to infections, including the use of concomitant immunosuppressive medications.

Serious infections: Serious infections, including sepsis, due to bacterial, mycobacterial, invasive fungal, parasitic, viral, and other opportunistic infections such as islatrisis, and pneumocystis have been reported in patients receiving Humira. Other serious infections seen in clinical trials include pneumonia, pyelonephritis, septic arthritis and septicaemia. Hospitalisation or fatal outcomes associated with infections have been reported.

Tuberculosis: There have been reports of tuberculosis in patients receiving Humira. It should be noted that in the majority of those reports, tuberculosis was active/pulmonary, i.e. disseminated. Before initiation of therapy with Humira, all patients must be evaluated for both active or inactive (latent) tuberculosis infection. Appropriate screening tests, should be performed in all patients; local recommendations may apply. If active tuberculosis is diagnosed, Humira therapy must not be initiated. If latent tuberculosis is suspected, a physician with expertise in the treatment of tuberculosis should be consulted and the benefit/risk balance of therapy with Humira should be considered. If inactive (latent) tuberculosis is diagnosed, appropriate treatment must be started with anti-tuberculosis prophylaxis therapy before the initiation of Humira, and in accordance with local recommendations. In patients who have severe or significant risk factors for tuberculosis and have a negative test for latent tuberculosis, anti-tuberculosis therapy should also be considered before the initiation of Humira. In patients with active tuberculosis in whom an adequate course of treatment cannot be confirmed. Some patients who have previously received treatment for latent or active tuberculosis have developed active tuberculosis while being treated with Humira.

Other opportunistic infections: Opportunistic infections, including invasive fungal infections have been observed in patients receiving Humira. These infections have not consistently been recognised in patients taking TNF-blockers and thus resulted in delays in appropriate treatment, sometimes resulting in fatal outcomes. For patients who develop the signs and symptoms such as fever, malaise, weight loss, sweats, cough, dyspnoea, and/or pulmonary infiltrates or other serious systemic illness with or without concomitant cough, an invasive fungal infection should be suspected and administration of Humira should be promptly discontinued. Diagnosis and administration of empiric antifungal therapy in these patients should be made in consultation with a physician with appropriate expertise.

Hepatitis B Reactivation: Reactivation of hepatitis B (HBV) has occurred in chronic carriers receiving Humira, with some fatal outcomes. In patients who develop HBV reactivation, Humira should be stopped and effective anti-viral therapy with appropriate supportive treatment should be initiated. Carriers of HBV should be closely monitored for signs and symptoms of active HBV infection throughout therapy and for several months following termination of Humira.

Neurological events: Humira has been associated, in rare cases, with new onset or exacerbation of clinical symptoms and/or radiographic evidence of demyelinating disease including multiple sclerosis. Caution should be exercised when considering Humira in patients with pre-existing or recent onset central nervous system demyelinating disorders.

Allergic reactions: Postmarketing serious allergic reactions including anaphylaxis have been reported very rarely. If an anaphylactic reaction or other serious allergic reaction occurs, administration of Humira should be discontinued immediately and appropriate therapy initiated. The needle cover of the syringe contains natural rubber (latex). This may cause severe allergic reactions in patients sensitive to latex.

Malignancies and lymphoproliferative disorders: In clinical trials, more cases of malignancies including lymphoma and leukaemia have been observed among patients receiving a TNF-antagonist compared with control patients. These data cannot exclude a possible risk of malignancy in patients including children and adolescents treated with TNF-antagonists. Furthermore, there is an increased background lymphoma risk in RA patients. Rare postmarketing cases of hepatosplenic T-cell lymphoma have been identified in patients treated with adalimumab. Some of these cases have occurred in young adult patients on concomitant treatment with azathioprine or 6-mercaptopurine used for Crohn's disease. A risk for the development of hepatosplenic T-cell lymphoma in patients treated with Humira cannot be excluded. Caution should be exercised in considering Humira treatment of patients with a history of malignancy. All patients, and in particular patients with a medical history of extensive immunosuppressant therapy or psoriasis patients with a history of PUVA treatment should be examined for the presence of non-melanoma skin cancer prior to and during treatment with Humira. Caution should also be exercised when using TNF-antagonists in COPD patients, as well as in patients with increased risk of malignancies due to heavy smoking.

Haematologic reactions: Pancytopenia including aplastic anaemia has rarely been reported with TNF blocking agents. Adverse events of the haematologic system, including cytopenia (eg thrombocytopenia, leucopenia) have been reported with Humira. Patients should be advised to seek immediate medical attention if they develop signs and symptoms suggestive of blood dyscrasias.

Vaccinations: Patients on Humira may receive concurrent vaccinations, except for live vaccines. It is recommended that JIA patients, if possible, be brought up to date with all immunisations in agreement with current immunisation guidelines prior to initiating Humira therapy.

Congestive heart failure: Humira should be used with caution in patients with mild heart failure (NYHA class I/II) and discontinued in patients who develop new or worsening symptoms of congestive heart failure.

Autoimmune process: Humira may result in the formation of autoimmune antibodies. If a patient develops symptoms suggestive of a lupus-like syndrome following treatment with Humira and is positive for antibodies against double-stranded DNA, further treatment with Humira should not be given.

Surgery: There is limited safety experience of surgical procedures in patients treated with Humira. The long half life of Humira should be taken into consideration when a surgical procedure is planned, and the patient should be monitored for infections.

Small bowel obstruction: Failure to respond to treatment for CD may indicate the presence of fixed fibrotic stricture that may require surgical treatment. Available data suggest that Humira does not worsen or cause strictures.

Elderly population: The frequency of serious infections among Humira treated subjects over 65 years of age was higher than those under 65 years of age. Some of those had a fatal outcome. Particular attention regarding the risk for infection should be paid when treating the elderly.

Interactions:

Combination of adalimumab with anakinra or abatacept is not recommended.

Pregnancy and lactation:

Administration of adalimumab is not recommended during pregnancy. Women of childbearing potential should use adequate contraception and continue its use for at least five months after the last Humira treatment. Women must not breastfeed for at least five months after the last Humira treatment.

Driving and machinery:

Humira may have a minor influence on the ability to drive and use machines.

Side Effects:

Very common $\geq 1/10$: Respiratory tract infections (including lower and upper respiratory tract infection, pneumonia, sinusitis, pharyngitis, nasopharyngitis and pneumonia herpes viral), leucopenia (including neutropenia and agranulocytosis), anaemia, limbs increased, headache, abdominal pain, nausea and vomiting, elevated liver enzymes, rash (including exfoliative rash), musculoskeletal pain, injection site reaction (including injection site erythema). Common $\geq 1/100$ to $< 1/10$: Systemic infections (including sepsis, candidiasis and influenza), serious infections (including gastroenteritis viral), skin and soft tissue infections (including paronychia, cellulitis, impetigo, necrotising fasciitis and herpes zoster), ear infections, oral infections (including herpes simplex, oral herpes and tooth infections), reproductive tract infections (including vulvovaginal mycotic infection), urinary tract infections (including pyelonephritis), fungal infections, benign neoplasm, skin cancer excluding melanoma (including basal cell carcinoma and squamous cell carcinoma), thrombocytopenia, leucocytosis, hypersensitivity, allergies (including seasonal allergy), hypokalaemia, uric acid increased, blood sodium abnormal, hyperkalaemia, hyperglycaemia, hypophosphataemia, blood potassium increased, mood alterations (including depression), anxiety, insomnia, paraesthesiae (including hypoaesthesia), migraine, scaldia, visual impairment, conjunctivitis, vertigo, bradycardia, hypertension, flushing, hemicrania, cough, asthma, dyspnoea, GI haemorrhage, dyspepsia, gastroesophageal reflux disease, sicca syndrome, pruritis, urticaria, bruising (including purpura), dermatitis (including eczema), onychocystis, hyperhidrosis, muscle spasms (including blood creatine phosphokinase increased), headache, renal impairment, chest pain, oedema, coagulation and bleeding disorders (including activated partial thromboplastin time prolonged), autoantibody test positive (including double stranded DNA antibody), blood lactate dehydrogenase increased, impaired healing. Uncommon $\geq 1/1000$ to $< 1/100$: Opportunistic infections and tuberculosis (including coccidioidomycosis, histoplasmosis and mycobacterium avium complex infection), neurological infections (including viral meningitis), eye infections, bacterial infections, joint infections, lymphoma, solid organ neoplasm (including breast cancer, lung neoplasm and thyroid neoplasm), melanoma, idiopathic thrombocytopenic purpura, dehydration, tremor, blepharitis, eye swelling, diplopia, deafness, trinititis, arrhythmia, congestive heart failure, chronic obstructive pulmonary disease, interstitial lung disease, pneumonitis, pneumonia, trinititis, dysphagia, face oedema, cholelithiasis and cholelithiasis, bilirubin increased, hepatic steatosis, night sweats, scar, rhinophyma, nocturia, erectile dysfunction, inflammation. Rare $\geq 1/10,000$ to $< 1/10,000$: Pancytopenia, multiple sclerosis, cardiac arrest, vascular arterial occlusion, cardiac aneurysm, thrombophlebitis, systemic lupus erythematosus. **Postmarketing surveillance and phase IV clinical studies side effects:** Reactivation of hepatitis B, intestinal perforation, hepatosplenic T-cell lymphoma, leukaemia, demyelinating disorders (eg optic neuritis, Guillain-Barré syndrome), cerebrovascular accident, anaphylaxis, cutaneous vasculitis, Stevens-Johnson syndrome, angioedema, new onset or worsening of psoriasis (including palmoplantar pustular psoriasis), lupus-like syndrome, myocardial infarction, diverticulitis, pulmonary embolism, erythema multiforme, alopecia, pleural effusion.

Prescribers should consult the summary of product characteristics for further information on side effects.

Overdose:

No dose-limiting toxicity was observed during clinical trials. The highest dose level evaluated has been multiple intravenous doses of 10 mg/kg (approximately 15 times the recommended dose).

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Pre-filled Pen: Each carton contains 2 pre-filled pens, each with 1 alcohol pad, in a blister. Pre-filled Syringe: Each carton contains 2 single use pre-filled syringes (type I glass) for patient use and 2 alcohol pads.

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Store in a refrigerator at 2 - 8 °C. Keep in the outer carton, do not freeze.

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Marketing Authorisation Numbers:

EU/1/03/256/002-005, EU/1/03/256/007-010

Further information is available from Abbott Laboratories Ireland Ltd, 4051

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Date of revision of Pt. July 2010 Pt256/002

Building Consensus

What a wise decision by the ECCO Governing Board – in retrospect!

It must have been in 2003, i.e. two years after founding ECCO, that I was given the opportunity to present to the Board a vision of a European Consensus on Crohn's Disease Diagnosis and Treatment, and subsequently another one on Ulcerative Colitis. As a newcomer to ECCO I was greeted with friendly scepticism. Nevertheless, Renzo Caprilli, Miquel Gassull and Geert D'Haens, as key members of the Governing Board, understood the notion that a Consensus process would not only build a network of productive scientific and social interactions within the organisation, but also, if everything worked out, crystallise a text to be used as a standard reference by specialists and non-specialists in IBD in Europe and elsewhere. Pierre Michetti, much more eloquent, suggested another, alternative approach, at the same Board meeting: The EPACT Council of fewer experts, but using a well defined decision-making process. It was decided to support both – also extremely wise, because both approaches succeeded in the end.

The task was formidable. It helped that I had previously organised the German Consensus and, as a result, had some experience with strong egos. In hindsight, the European Consensus was easier to manage! The process involved selecting the active participants, none of whom expected so much time and effort to be associated with their consent to take part. Thirteen working (in the strict sense

of the word) parties were formed, from "clinical diagnosis and imaging" to "alternative therapies". Their leaders were Walter Reinisch, Karel Geboes, Stefan Schreiber, Simon Travis, Marc Lémann, Tom Øresland, Renzo Caprilli, Miquel Gassull, Johanna Escher, Pia Munkholm, Gabriele Moser, Colm O'Morain and Daan Hommes. In total, 63 experts were recruited from twenty different European countries, including Israel. The largest delegation came from Italy, contributing considerably to the positive atmosphere of the process, followed by the United Kingdom providing expert native speakers for the later text. Simon Travis took the lead and co-chaired the whole process.

As a first step, the working parties had to devise the relevant questions for each of the various topics. All participants had to respond to the questionnaires based on their experience and evidence from the literature. This "evidence base" proved to be the key to providing recommendations that are as objective as possible and helped quantify opinion. When guidelines depend solely on published results, common sense can be a casualty. The questionnaires were provided by the working parties based on a systematic literature search with the appropriated key words which had to be laid open. The evidence was then graded according to the Oxford Centre for Evidence Based Medicine. Provisional guideline statements were then written by the Chairmen of the working parties, based on the evidence as well as the questionnaire results and were then circulated among the participants.



Consensus Meeting on the Management of Opportunistic Infections, Nice, 2007



Consensus Meeting on the Management of Opportunistic Infections, Nice, 2007

Following these extensive preparations all working parties met in Prague on September 23, 2004 to agree the final version of each guideline statement. These were projected on a screen and revised until a consensus was reached. This was defined as agreement with the precise wording by >80% of the participants; between 50-80% in agreement was termed a "majority" vote. The result, in my view and that of most others, was pretty good but far from perfect. Sometimes during these sessions a controversy suddenly focused on a ridiculously peripheral issue and some major recommendations just passed the panel with surprisingly little discussion. It seems, at least in my memory, that these were rather relaxed times before the nasty anti-TNF fights and the top down/step up question. Both, the Consensus meeting and the social parts were fun and many friendships were formed. Considering that all participants were leading experts in their country, none of them type B personalities, and that all their countries treat patients and handle their resources somewhat differently, our success could not be taken for granted. Having invested so much of my own time and reputation in this effort, I was quite relieved.

The final text took a while to be written, since the 14 sections had to be redrafted into three papers, format collated and English polished by Simon, comments agreed and the naked statements put into context for clarity and explanation. Three manuscripts on "definitions and diagnosis", "current management" and "special situations" were submitted to Gut, then reviewed (by S. Hanauer and W. Sandborn, who wrote a leading article on the Consensus), accepted and finally published as a supplement in March 2006. The three articles have been quoted over 600 times

and were all in the top ten quoted papers of this eminent journal in 2007. The ECCO Guideline on Crohn's Disease has achieved its purpose: To provide the first comprehensive set of evidence-based recommendations in this disease for Europe and maybe beyond. Notably, this contrasts with American style "practice guidelines" which are conceived by a small set of (often self-) selected experts, which lack the necessary formal approach described above.

However, after the Consensus is before the Consensus.

The next major task was to rejuvenate the group and devise the Consensus on Ulcerative Colitis. Essentially, the same procedures were used and the group met in Berlin in October 2006. This time the guideline paper was submitted to our own ECCO Journal, the Journal of Crohn's and Colitis, and was published in 2007.

In the meantime Axel Dignass and Gert van Assche have taken over the lead and should be congratulated on how they improve the process. All guidelines have to be regularly updated, nothing should be chiselled in stone. Quo vadis, where are the pitfalls? It is obvious that the pharmaceutical industry has a vital interest in the content of our recommendations since the companies are commercially affected: Sometimes in an adverse fashion (for example when ECCO states that Mesalazine has only limited activity in Crohn's Disease) or positively (for example when use of anti-TNF compounds should be considered "upon relapse", i.e. every patient sooner or later). It is therefore of paramount importance that ECCO and its

Consensus process steer clear from industry interests. Otherwise, we lose all credibility in the independence of our recommendations. Admittedly, in the real world this is difficult to achieve, but seeing the danger helps a lot: Ulysses made it in the end.

Eduard Stange

ECCO and Industry:

Partners along the road



Renzo and Paola Caprilli with Gian Carlo Naccari, 2000

The golden age

In 1997, ten years after the launch of the first modified-release Mesalazine in Italy, the market for this product had reached about two million units per year. We were worried and intimidated at Giuliani SpA by the imminent arrival of new “substances” called monoclonal antibodies,

developed by an innovative American company. The time had come to prepare for battle for a substance that was certainly not innovative, like Mesalazine, to redesign its features, prolong its release profile, ensure coverage of the entire colon and to improve patient compliance.

At that time, I had the good fortune to meet again the eminent Prof. Renzo Caprilli, a Tuscan to the core (Tuscans are well known in Italy for their proverbial resourcefulness and wilfulness), a Professor of Gastroenterology at the University of Rome "La Sapienza". He had also founded the GISC Group (Italian Colon-Rectum Study Group), which brought together more than 60 centres with IBD as its primary focus and specialisation. Our professional interaction, aimed at expanding the knowledge of IBD, was so passionate (often marked by creatively contrasting ideas) and intense that it led to our deep, personal esteem and we also became true friends (as we still are, indeed!).

This extremely close relationship led Giuliani SpA, in 1999, to be the first company aware of the original idea behind the "European IBD National Group", of the meeting in Rome with

Geert D'Haens at the 7th UEGW and, later, of the evolution of the name into ECCO (Voilà).

In the following years I witnessed the evolution of the objectives and initiatives of ECCO. I attended the meeting in Geneva which officially gathered the Corporate Members (five from the entire pharmaceutical world of IBD: Giuliani, Falk Pharma, Ferring, Centocor and PDL). On that occasion, the representatives of these companies were given the opportunity to present both their existing and early stage projects, provided they focused on IBD. During the official meeting I personally gained a further advantage: I was able, at last, officially to justify the entry "ECCO" into the company's budget (no longer included in the anonymous entry "Conventions and Meetings") and, as a Corporate Member, I was able to address the elected audience of ECCO's Presidential Committee (GB).



Three Presidents and a friend, Amsterdam, 2006

An intensive and austere meeting in Sardinia

In 2005 the Intensive Clinical Course for residents, fellows and junior faculty was held at Poltu Quatu in Sardinia (strangely enough, the local organiser was Prof. Renzo Caprilli). No longer being a young student who could be admitted to the course room, I revelled in the opportunity to spend my free time with leading international teachers in a relaxed atmosphere that further strengthened our friendship. This is unlike other meetings where everything is much more hectic and influenced by too short a schedule. We had pleasant, relaxing moments in the mild spring temperatures of about 16-18 degrees (a great and sturdy champion like Tom Øresland, obviously accustomed to different temperatures, even dared to bathe in the pool). We dined in a splendid and friendly atmosphere, accompanied by typical Sardinian dishes in the beautiful atmosphere of the bay lying beneath us.



3rd ECCO Course in Poltu Quatu: A nice bay, Sardinia, 2005

The maturity

With the rising importance of the ECCO Congress and of the meetings between Corporate Members and IBD leaders, in 2007 I was appointed by my pharmaceutical industry colleagues as a “senior manager” (in the original Latin sense = oldest), and started giving voice to the first complaints to be brought to the Presidential Committee (GB); I believe that this was a clear sign of the growth and vitality of the group.

The main diatribe, recurring since the early years of ECCO, was the short time devoted to companies at the National Representatives’ annual meeting. Sponsors were allowed to make a quick three-minute presentation (whether these were small, medium-sized or large companies) dedicated to the strategic research and development of new projects. Yet, this happened in the last half hour of the meeting, usually running behind schedule and pressed by the urgent need to go to the social dinner.

I was thus asked by President Miquel Gassull to lodge an official complaint on behalf of the Corporate Members. Our “cahier de doléances” was brilliantly addressed, devoting the time and attention that the sponsors deserved. The Corporate Members’ Meeting, held under the watchful eye of its Presidents, yesterday Jean-Frédéric Colombel and today the newly elected Daan Hommes, is an important opportunity for updated exchanges of information and communication with IBD centres, with the obvious advantage of receiving crucial advice in return. The omnipresence of the representatives of the various European countries gives a further opportunity to the pharmaceutical industry



Starring at Jean-Frédéric Colombel, 4th Congress of ECCO, Hamburg, 2009

focusing primarily on IBD, namely that of identifying influential centres to improve the recruitment of IBD patients in multinational protocols.

The next hundred years

The participation in the ECCO meetings, the promotion of contacts with European quality centres and the support offered by the ECCO Office in Vienna have been very important to Corporate Members. This interaction has offered fertile ground for the development of new ideas on new methods of drug administration, management and care, all validated to the benefit of patients. This has been and will be the case for the growth of Cosmo (where I am Senior (again !?!?) Vice President since 2006) with its headquarters

in Italy, and has been able to develop the new technology MMX for the intestinal release combined with classic active ingredients, of which the first example was Mesalamine (Lialda, Mezavant), now followed by Budesonide MMX, Rifamycin MMX and LMW Heparin. Cosmo has been able to build alliances with traditional companies in the IBD industry, such as Giuliani, Shire, Ferring and Falk Pharma, relying on the "ECCO Seal of Quality".

Now, a special request to ECCO:

A peak moment of the social life of ECCO is, for sure, the social dinner (ECCO Interaction) followed by singing and dancing in a liberating, university-spirit atmosphere. The only true inadequacy of this event is that I have never had the chance to perform



The preliminary formal contact with the President-Elect, wife Pamela and daughter Clementine

live as an Italian crooner (some of the great leaders of the IBD world already know me as a singer and can testify to this). Therefore, I hereby formally apply to the Governing Board (including Simon Travis, the President-Elect, whom I have begun preliminary talks with for purely professional and scientific reasons) to perform as a singing attraction at the official dinner, starting from the one to be held in Dublin, even if my voice will not be in line with traditional Irish singing.

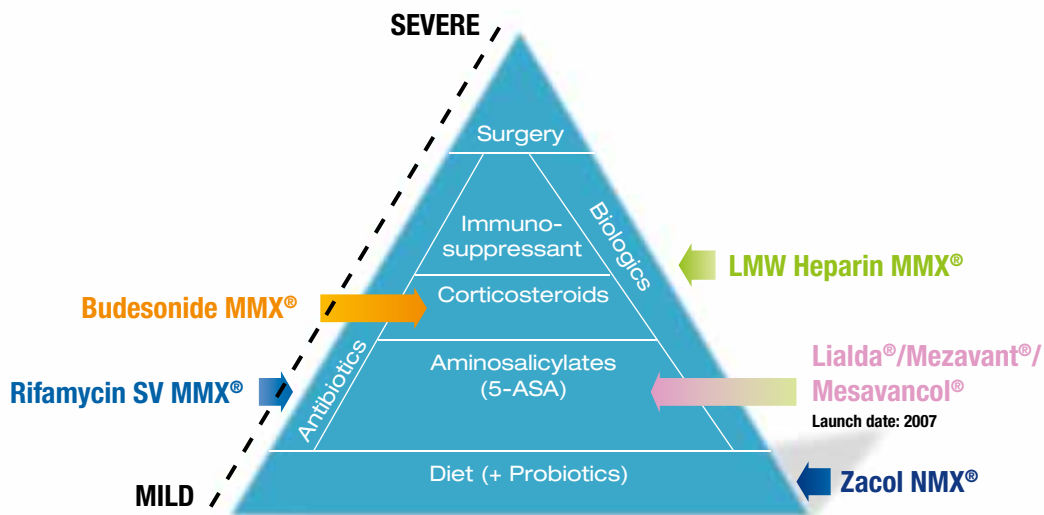
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- MMX Technology: EP 1,183,014
- Mesalamine MMX: EP 1,198,226
- Budesonide MMX: US 7,410,651 – EP 1,183,014
- Heparin MMX: EP 1,992,338
- Rifamycin MMX: EP 1,763,339
- Butyrric Acid/Inulin MMX: PCT/EP/05707903

The National Groups:

What has ECCO meant to us?

The original idea of the founders of ECCO was the constitution of an organisation of the National IBD Study Groups.

The main aim of ECCO was the optimisation of the care of patients with IBD in Europe. Further aspects of the mission of ECCO included the promotion of post graduate education and of scientific projects in IBD.

After the initial adhesion of five countries in 2001, most of the European countries joined ECCO in the following years.

Each country nominates two representatives who have a seat in the Strategic Council of ECCO

as well as in the General Assembly with the right to vote, where they represent their country and hence their National IBD Study Group.

In 2006, with the great increase of interest in ECCO activities among European gastroenterologists, the opportunity to introduce individual membership to foster the relationships among people was discussed and finally implemented in 2008.

As of January 1, 2011 ECCO counts 31 European countries as its members (including Israel) and the number of individual members is rising constantly.

The narratives of some National Representatives are outlined in this chapter.



ECCO Country Members as of January 2011

Austria



ECCO and an Austrian family affair



Herbert Tilg (leftmost) and Walter Reinisch (rightmost) congratulate the winners of the annual IBD award for the best publications at the meeting of the National IBD Study Group, Weyregg, Austria, 2008

For the first ten years the savings of ECCO have been parked safely in Austrian accounts. *"Our money is safe in Austria"* was a frequent quote by Herbert Tilg who followed me as Treasurer of ECCO and prolonged the tradition of bringing the fruits of ECCO's fortune to Austria. But how did it come that Austria was appointed with this responsible task initially? It's worth shedding some light on this issue and revealing some family bonds behind it. At the time ECCO assembled in 2001, Austria already had experience in running a National IBD Study Group which was founded in 1994 by Wolfgang Petritsch. The group is part of the Austrian Society of Gastroenterology and Hepatology and the election of its leadership has always been subject to the democratic process of a ballot vote. The group was initially focusing on educational tasks and the publication of consensus reports. In 2001, members of the Austrian IBD Study Group already

had strong individual relationships with physicians and researchers with a focus on IBD within Europe and on a global scale, but we were clearly missing the official collaboration with other European study groups. Under the leadership of Harald Vogelsang in 2001, our group was keen to follow the call of merging interest in a European IBD group. To our surprise we realised that despite the tremendous research efforts on IBD across Europe only few countries had official study groups in place. Thus, the Austrian IBD Study Group based on its expertise took advantage of the momentum and hosted the first meeting of this new European group in Vienna in which two delegates from Austria, the head at that time and me, participated.

I was really excited about the idea of starting an IBD Study Group in Europe and to spread its spirit over Europe. I was also keen on becoming a member

who could assist and guide the process. However, how could I help in this early phase? I had some ideas on how an organisation is assembled and therefore was wondering who would be willing to take over the responsibility of raising and governing the finance. Frankly speaking, at that time I did not have any major experience in monetary affairs of that size and if any personal questions arose I asked my mother for assistance! She used to work as a bookkeeper for a mid-size company during her working life and was always full of advice when financial issues came up. In 2001, she had already been retired for a while but still busy ensuring the financial welfare of our family. A few days before the new European IBD Study Group convened in Vienna she became sick and had to be hospitalised. I visited her daily. A day before the meeting I told her about my idea of applying for the job as Treasurer. However, to my disappointment my mother was not supportive. She explained that such a job is supposed to be highly responsible, but barely visible from outside. *"You will always need to chase money, as no one is willing to pay voluntarily"* she argued further. *"Be careful"* she called after me, when I was leaving the hospital room.

The next morning a small group of European experts in IBD convened enthusiastic about the idea of forming an IBD group in Europe. The atmosphere was friendly and some of us felt that an important idea should be realised. Nevertheless, when it came to the time to appoint the Treasurer barely any commitment could be obtained from the group. Disregarding the warnings from my mother I volunteered myself, feeling slightly unsure as to how to fill this role without personal experience. But in the end, the honour of becoming an active part in a European IBD Study Group outweighed any concerns.

After the meeting I visited my mother in the hospital again. She seemed to be very tired and close to sleep. I simply sat by her side and waited. After a while she murmured: *"Did you take the job?"* I

was surprised by the tone and even before I could answer, she went on: *"Yes, you did take the job, you wouldn't have been my son if you did any different."* In a friendlier and softer tone she added: *"I'm proud of you". "Yes, I became Treasurer of a new group in which I absolutely believe in and you will help me to achieve the goals."* As I said this I could feel her energy rising and maybe coincidentally or even driven by a new task she recovered rapidly and was discharged after only a few more days in hospital.

Within the following weeks and months she taught me the documentation and descriptive reporting of book keeping and how to chase errant partners for payment. During those first years of ECCO, its savings grew continuously despite our growing expenses. Finally when I handed over the accounts to Herbert Tilg in 2005 who was Head of the Austrian IBD Study Group at that time, ECCO was moneywise on the safe side and could conceive on embarking in the congress business.

Every now and then my mother still asks me about that European society in which I started as Treasurer. When I mentioned recently that we are meanwhile hosting a congress up to 3,000 attendees she was proud to have lent her helping hand in its early days.

Walter Reinisch

Belgium



Belgian IBD Research Group "flies"



Belgian IBD Research Group (BIRD), 2010

The Belgian IBD Research Group recently renamed "BIRD" celebrated its 10th anniversary last year in 2010. At this occasion the new name and a new logo were introduced.

As a real teenager the group is "alive and kicking" with quarterly highly attended meetings by colleagues (including paediatricians) from all academic institutions and from regional private centres around the country and an annual scientific symposium during the Belgian Week of Gastroenterology.

You certainly know our group from studies as "The Step up/Top Down Trial". But watch out for us in the near future as we have currently a lot ongoing (and about) to start clinical research projects both registries and observational studies (e.g. paediatric IBD, vaccinations, calprotectin in UC, adalimumab, TPMT) and interventional studies some in cooperation with other countries: France, Spain (e.g. Adagio, Adacal, Tailorix).

Filip Baert, Denis Franchimont



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Bulgaria



Joining the ECCO Family



Faculty of the 18th ECCO Educational Workshop, Sofia, 2010

The Bulgarian IBD Association was established in 2006 as a local organisation of gastroenterologists and IBD specialists. Afterwards, a small number of paediatricians and pathologists joined the association. The goal was to improve the information flow and to maintain educational programmes on modern and contemporary ethiopathogenetic approaches to the diagnosis and treatment of IBD patients. The same year, the Bulgarian IBD Patients Organisation was founded.

In 2007, Bulgaria became a member of the European Union and several months later

the Bulgarian IBD Association was invited to join ECCO. Our first contacts with ECCO were established with the ECCO Scientific Committee and Boris Vucelić, who invited us to become a member of ECCO. The society then became an ECCO Member in order to implement the EU standards of diagnosis and treatment of IBD.

The National Representatives were elected by the national IBD association – Assoc. Prof. Zoya Spassova from University Hospital “St. Ivan Rilski”, Sofia and Prof. Iskren Kotzev from University Hospital “St. Marina”, Varna.

The ECCO Office team was always available for help and advice during our first steps of being a member of ECCO. With their support and professional advice we were able to send our young gastroenterologists to take part in several extremely creative activities of ECCO like the Advanced IBD Course as well as the ECCO Educational Workshops.

A great challenge, but also a big responsibility and pleasure, was to be the host of the 18th ECCO Educational Workshop in Sofia on November

11, 2010 with special participation of ECCO President Prof. Daan Hommes, as well as of Prof. Rami Eliakim. Their lectures were extremely interesting, helpful and with practical direction. The membership in ECCO provides a great opportunity for good scientific and educational experience for Bulgarian gastroenterologists. ECCO also gives us the possibilities to learn and apply the modern European standards for diagnosis and management of IBD patients.

Zoya Spassova, Iskren Kotzev

Czech Republic



ECCO and the Czech National IBD Group: Inspiration and tradition



Czech IBD working group at the national meeting, 2010

To mention one of the most intense personal memories of ECCO, I need to go back to the year 2003. At the beginning of May in this year, ECCO, in close cooperation with Milan Lukáš and Charles University in Prague, had organised the first Intensive Clinical Course for residents, fellows and junior faculty in Prague, Czech Republic. We were aware of this upcoming event several months in advance, and we decided to organise a “Dress-Rehearsal”. Therefore, the Czech National IBD Group led by Milan Lukáš organised the first Intensive Course on IBD for Czech junior doctors in December 2002. It was very successful and, year by year, it

has become the most popular IBD event in the Czech Republic.

Another thing that I’ll always remember is my participation at the first Intensive ECCO Course in Prague. There were slightly more than 30 participants attending the course from all over Europe. Besides my Czech colleague Marek Benes and Tibor Hlavaty from Slovakia, all the others were “unknown” to me at that time. Nevertheless, one person was a bit more “visible” among others – this was a young, fair-haired girl with profound knowledge of most aspects of IBD. We had several talks during the course and also during the nice dinner at the Břevnov

monastery, when she told about her stay at the Montreal University Hospital a couple of years before. This was Séverine Vermeire who took part in the first IBD Intensive Course together with me.

In general, the Czech National IBD Group was inspired by ECCO several times. Besides the intensive course mentioned above, we also tried to prepare a national consensus on the diagnostics and management of Crohn's Disease and Ulcerative Colitis, and most recently, guidelines on the prevention and therapy of opportunistic infections in IBD patients on immunosuppressive therapy.

The history of ECCO in my country is inseparably connected with Prof. Milan Lukáš. He was among the first people establishing ECCO as an umbrella of the National IBD Groups, and he was

also the main "promoter" of this organisation throughout the gastroenterological society not only in the Czech Republic, but also among our friends in Slovakia. Since the very beginning, he served as the National Representative of my country within ECCO. Two years ago, he stood for election for the position of ECCO Treasurer and was very close to achieving this position. It is to Milan's credit that we could welcome the 5th ECCO Congress in Prague in February 2010. As Milan has decided to step aside as a National Representative at the end of 2010, I would like to express my personal thanks for everything he had done in this position. It is my hope that he will continue in close cooperation with me and the new National Representative Tomas Douda.

Martin Bortlík

Finland



Being involved with ECCO



Franck Carbonnel (France) and Martti Färkkilä (Finland), Prague, 2010



Taina Sipponen and Perttu Arkkila (Finland), Lyon, 2008

Finland, a Nordic country with about 5.3 million inhabitants, became a member of ECCO in 2004. The activities of Finland during the first years of ECCO consisted mostly of taking part in the yearly meetings and some laziness in paying the annual country membership fee.

However, Finns have been actively taking part in the ECCO IBD Courses. Since 2007, we have sent two to three participants to the ECCO Course each year. The participants have been very satisfied with the course: "Best IBD Course ever" has been heard almost after every junior course. Contact of our geographically distant and northern country with other ECCO Country Members has been important. We have had the pleasure of inviting a foreign ECCO lecturer to our yearly IBD meeting, to name just one example. We always considered these contacts – both scientific and personal – very important. In addition, the educational connection may become closer as well in the future as Finland is hosting an ECCO Educational Workshop in 2011. The scientific activity of the Finnish group in ECCO is slowly, but steadily growing. We are

taking part in the CYSIF study, in the IBDIS validation project, and in the H1N1 vaccination study. Moreover, Finland is also beginning to recruit patients to the METEOR study. Interest in presenting Finnish IBD research posters at the annual ECCO Congress and also submitting manuscripts to the JCC has increased significantly over the past years. Participation in the ECCO Congresses has grown rapidly in our country and many participants have especially enjoyed the "ECCO Spirit" at the traditional ECCO Interaction: Hearts and Minds at one of the past ECCO Congresses.

Taina Sipponen, Martti Färkkilä



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GIULIANI

France



What has ECCO meant to us?



Marc Lémann together with Arlette Darfeuille-Michaud and Jean-Frédéric Colombel

So many things: Travelling, working, broadening our views, exchanging ideas, arguing, and dancing (thanks to W. Reinisch).

In a very few years we have done so many things together. Multicenter institutional European trials such as CYSIF and METEOR have been set up and are performed under the auspices of ECCO. We have participated in consensus conferences, educational sessions, workshops, and many meetings across Europe. We have spent a lot of time at airports, in aeroplanes and taxis. But at the same time, we have met many people from all over Europe, outside our narrow circle, with different views and conceptions. ECCO has also given our fellows and nurses a

fantastic opportunity to broaden their point of view and knowledge through educational activities of ECCO such as the ECCO Educational Workshops. What we have not well done so far is to convince other French gastroenterologists to join ECCO. However, this is our goal for the next few years!

An "ECCO attitude" emerged. I cannot find better words than "cool, open and professional" to describe it. But it is not only a matter of work. It is also friendship. We became so close to many colleagues in a very short period of time. It is not just superficial relationships but real friendship. In August 2010, we lost our friend and leader Marc Lémann. We received many friendly messages from everywhere in Europe. Also,

many ECCO Officers came to Paris for Marc's funeral and shared our sadness. This, we will never forget.

Marc was extremely enthusiastic about ECCO. He adored the meetings and discussions (scientific and extra scientific). He could argue for hours with European colleagues. He was happy then. It was his life.

We will continue Marc's work. ECCO is a very young group. It can accomplish great things. New ideas and projects have arisen.

We will take part in all the actions and initiatives of ECCO and importantly, we will preserve the "ECCO Spirit".

Franck Carbonnel

Greece



Hellas



Members of the Governing Board of EOMIFNE, 2009-2010

Well back in about the mid-90's, a relatively small group of local gastroenterologists headed by Dimitrios Karamanolis at that time and soon joined by George Kitis and Epaminondas Tsianos envisaged the need for further education and training in the field of Inflammatory Bowel Diseases (IBD) in Greece.

They initiated annual informal meetings in the field of IBD which, from the very beginning, became extremely popular and very well attended by gastroenterologists from all over the country.

This very successful initiative subsequently led to the formation of the Hellenic IBD Study Group (EOMIFNE) in the year 2000. Since 2002, EOMIFNE holds its annual congress with great success attracting hundreds of participants and the scientific programme always lists distinguished invited speakers from all over the world. Our group presently comprises about 300 members (gastroenterologists, paediatricians, surgeons, radiologists, pathologists and basic scientists). The group collaborates closely with other medical societies as well as IBD patient organisations.

In 2001, the then President of EOMIFNE George Kitis was informed about the formation of ECCO. Envisaging its very promising potential based on its structure, aims, capacity of its founding members and clear statutes, EOMIFNE joined ECCO as an official member under the presidency of Renzo Caprilli.

Since then Greece has joined and supported every ECCO activity through EOMIFNE. A substantial number of participants from Greece attend the annual ECCO Congress and apart from national membership through EOMIFNE, Greece ranks favourably amongst other European countries in number of individual members within ECCO.

Members of the Hellenic IBD community have also actively participated in the in-depth and exhausting preparations and discussions which led in the publication of both the initial and recently revised guidelines for the diagnosis and management of Crohn's Disease and Ulcerative Colitis (published in Gut and JCC). The same applies for the two ECCO Pathogenesis Workshops held so far.

Regarding the several ECCO Committees, Greece is very successfully and efficiently represented in the Educational Committee by Gerassimos Mantzaris.

Several ECCO initiatives have greatly enhanced the educational, training and research activities of the Hellenic gastroenterological community in a variety of ways:

- Every year two to three junior gastroenterologists from Greece attend the ECCO Course preceding the ECCO Congress.
- Greece has hosted with great success the 4th ECCO Educational Workshop in Athens in September 2009 for the implementation of the ECCO Guidelines. (It is with great regret that we remember the late Prof. Marc Lémann who participated in this workshop along with Janneke van der Woude as official delegates from ECCO).
- Two junior gastroenterologists (Kostas Katsanos and Kostas Karmiris) were recipients of annual scholarships from ECCO for higher training in IBD.
- The "JCC – Journal of Crohn's and Colitis", the official publication of ECCO, represents a major tool in publishing IBD-related activities in both basic and clinical research.
- The published ECCO Guidelines form the major reference for the diagnosis and management of both Ulcerative Colitis and Crohn's Disease for the vast majority of gastroenterologists in Greece.

Regarding the latter, the ECCO Guidelines for Ulcerative Colitis were so popular among gastroenterologists in Greece that the Governing Board of EOMIFNE decided to translate them into Greek (after permission and approval from both ECCO and Elsevier) and now we are in the process of translating the revised ECCO Guidelines for Crohn's Disease.

In these days of severe financial crisis affecting almost all European countries (and Greece in particular) we hope and we feel confident that we will be able to continue with the help of ECCO to maintain and, hopefully, increase the services to our patients in every aspect of their disease. The same applies and for ourselves in continuing our contribution in the field of IBD research.

Last, but not least, we would like to express our gratitude to Nicole and her team, the driving force of the ECCO Office, for their sustained help and the management of the difficult task of keeping everything in the right order.

John Karagiannis



Front page of translated Greek edition of the ECCO Guidelines on the Diagnosis and Management of Ulcerative Colitis



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Hungary



What has ECCO meant to us?



Faculty of the 15th ECCO Educational Workshop, Budapest, 2010

I remember as if it were yesterday. The first discussion about Hungary joining ECCO came up during a conversation with Prof. Walter Reinisch in Vienna. He outlined the aims and perspectives of ECCO, suggesting that we should join ECCO to be able to extend our cooperative research to a fully European platform. At the same time, our research group at Semmelweis University had an intensive cooperation in hepatology with the Vienna University. Later we extended this work to the field of Inflammatory Bowel Diseases by bringing the Hungarian IBD Groups together, establishing the Hungarian IBD Study Group. The Group

became a successful platform for performing joint clinical research in genetics, serology, other biomarkers and clinical outcomes on national level. In 2004, I was invited to the ECCO General Assembly to present the Hungarian IBD Group where Hungary was officially accepted as a full member of ECCO. This opened a whole new horizon – we all felt that we became a member of a very supportive ECCO Family. For us, ECCO meant more than just a common forum of the leading IBD scientists, a circle for high quality scientific discussions and a platform for drafting interesting cooperative research projects; it also meant being among friends. I personally would

like to thank ECCO for the opportunity we were offered to become part of this European family. In the following years, ECCO fulfilled a lot of missions. The intensive ECCO IBD Course, the annual congress, the guidelines, the workshops – as well as the ECCO Interactions and friendships – all contributed to our growth. By joining ECCO, we had the opportunity to interact with truly visionary experts in IBD. For us, this was a clear victory, adding spice to our

further progress, being accepted, observing and discussing innovative, sometimes even “rebellious” new ideas. Finally, in the name of the Hungarian IBD Study Group, I would like to thank ECCO for giving us the opportunity to become part of its family and I do hope that with our continuous cooperation and common research, our group will be able to contribute further to the success of ECCO.

Peter Lakatos

Ireland



ECIBD and ECCO

Interest in Inflammatory Bowel Disease has increased exponentially in the past thirty years. Once it was the Cinderella subject in gastroenterology attracting few to pursue research and treatments were limited. However, it was clear that the disease affected young people and had disastrous effects on the quality of life of these patients. The only way to make progress was to develop a multidisciplinary approach involving basic scientists and all disciplines providing clinical services.

It was also clear that progress would only be achieved by collaboration and cooperating with other like-minded people throughout Europe. There has been a strong impetus to coordinate European endeavours through the creation of a European Union. Their coordination is slow when one considers that the Treaty of Rome was signed in 1957 but now is flourishing with 27 member states.

Gastroenterology has prospered with the creation of the United European Gastroenterology Federation in 1992. However, before that time those interested in IBD were involved in creating a European network. The stimulus to form this network was the observation that Crohn's Disease incidence in Galicia, Spain, was extremely low compared to the incidence in Northern Europe. This suggested a North South European gradient. This could be explained by environmental factors. Prof. Von Blankenstein and Dr. Shivanenda convened a meeting in Rotterdam, the Netherlands, of 13 interested parties and encouraged them to embark

on a quality assured population-based epidemiological study. In 1987 this initiative was continued by Prof. Stockbrugger at Maastricht. This initiative was funded by the EU and resulted in the publication of many prestigious articles and created a European Community IBD Group. This group met up to three times a year. Workshops were run to ensure the quality of the histological diagnosis. A panel of experts was set up to keep up with the diagnosis in difficult cases. An audit with visits to participating centres was organised. Best practices initiatives were highlighted and the quality of care improving on a patient centred service.

Many new ideas were formulated which created IBD nurse specialists, and exchange of doctors to experience other healthcare systems and cultures. Many PhD studies were completed. Lifelong friendships were formed. An inquiring mind, interest in research and quest for healthcare was facilitated. Involvement of patients was encouraged. Research findings were disseminated to the lay public empowering patients to be involved in their treatments. This encouraged patients to be enrolled into clinical trials of new treatment and saw the introduction of biological agents. It has created a family of European like-minded individuals who broke down frontiers and identified the challenges society faces in caring and treating patients who are diagnosed at a young age with a lifelong condition.

The ECIBD group born as a group with interest focused in epidemiology has now

successfully merged with the Epidemiology Committee of ECCO chaired by Pia Munkholm. The formation of ECCO, an organisation with interest in all aspects of IBD, has harnessed the excitement of research in treatments. It has ensured that Europe remains to the forefront of providing excellent care, and

pioneer and develop new more effective treatments for patients with Inflammatory Bowel Disease.

We are looking forward with renewed vigour with the incoming Chairperson Peter Lakatos.

Colm O'Morain

Italy



ECCO and IG-IBD



Some founders of IG-IBD, Rome, 1997

For many years a group of Italian gastroenterologists regularly meets to discuss clinical problems relating to Inflammatory Bowel Diseases. This study group was among the first to join ECCO, when it was founded by Renzo Caprilli together with other European researchers in 2001.

The organisation of ECCO was thereafter taken as a model for the institution of the Association of Italian IBD Study Group (named IG-IBD) and I had the privilege to be one of the founders and the first Secretary in the following years. I participated at several ECCO General Assemblies and National Representatives' meetings during

that time. There, I had the opportunity to appreciate the rigorous methods of discussion for the points listed on the agenda and the strict respect for the scheduled times. I believe that ECCO with its numerous initiatives (outstanding scientific meetings, workshops, cooperative studies, high level intensive courses) is really the organism that can build the future for all European national groups and enables them to become a unique entity and an institution where researchers can meet as friends.

Paolo Paoluzi



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Latvia



Our journey to ECCO



Faculty of the 16th ECCO Educational Workshop, Riga, 2010

The Latvian IBD Group joined ECCO in 2004 on the recommendation of our friend Prof. Limas Kupcinskis from Lithuania. There are many good and fine things associated with ECCO, but there was one dramatic situation in which the "ECCO Spirit" helped us in particular.

This story is about six ECCO Members from Latvia on their trip to the 6th IBD Intensive Advanced Course for junior gastroenterologists and the following 3rd Congress of ECCO, taking place in Lyon, France from February 27–28, 2008. In the early morning on February 26 the whole team Jelena Derova, Ieva Eglite, Valentina Lapina and myself Juris Pokrotnieks as well as two young gastroenterologists – Aleksejs Derovs

and Edgars Bodnieks departed from Riga for Lyon. Since there wasn't a direct flight from Riga to Lyon our group needed to change flights in Barcelona. We arrived in Barcelona on time and without rush boarded the next flight to Lyon. However, to our surprise, when we landed, we discovered that we had arrived in Leon, Spain instead of Lyon, France. Leon is the capital of a province in Spain. I immediately called the travel agent to find out why the tickets were purchased incorrectly. As it turned out, the travel agent misspelled the word Lyon and ordered tickets to Leon. Hence, we faced two major problems: Firstly, we had arrived at midnight (there were only two staff left at the airport and there was

no hotel nearby) and secondly, no one of the group could speak Spanish. Finally, we started to communicate in Spanish as best we could (the question was rather who remembered one and who remembered five words). Finally, we found a taxi and a nice hotel to spend the night. However, when we told the story to the receptionists in the hotel they just asked one question: *"Are you really from the European Union or not?"*

After spending one night in Leon, Spain we finally arrived in Lyon, France the next day where our other colleague who had organised the trip personally was waiting for us. We conclude from this experience that the vigorous "ECCO Spirit" helped us to arrive on time in Lyon in order to participate in all the activities of ECCO. Celebrate it together!

Jelena Derova, Juris Pokrotnieks

Portugal



What has ECCO meant to us (the Portuguese Group – GEDII)?



Faculty of the 7th ECCO Educational Workshop, Oporto, 2008

When we created the Portuguese Study Group on Inflammatory Bowel Disease in Portugal in March 2003, we faced a number of difficulties. These challenges were not only in respect to establishing an organisational model, but also how to stimulate research and improve the quality of treatment for IBD patients.

The inception of the European Crohn's and Colitis Organisation offered us a solid template and model of reference for our own development. Our participation in ECCO, formalised in 2004,

was undoubtedly a driving force behind the growth of the Portuguese Study Group on Inflammatory Bowel Diseases.

Our collaboration with ECCO puts us in contact with people widely experienced in establishing national groups, who had faced and overcome the kinds of difficulties we were beginning to experience. It was also thanks to ECCO that we met colleagues who enabled, through several visits to Portugal, the organisation of meetings on Inflammatory Bowel Disease, leading to

an improved and standardised approach to Portuguese IBD patients.

The 7th Educational Workshop, held in Porto in November 2008 and national meetings of the Portuguese IBD Study Group in January 2009 and January 2010 highlight the importance of the collaboration with ECCO. Many members of ECCO graced us with their presence in Portugal. It would be remiss not to acknowledge Marc Lémann, who personified the spirit and inspiration that ECCO represents to many of us. Participants like Marc did a lot to get ECCO recognised in Portugal, and established its annual meeting as the main event for Portuguese

physicians dedicated to Inflammatory Bowel Disease. Another example is the creation of an “Advanced IBD Course”, now in its ninth year, where young doctors have had the opportunity to broaden their knowledge in IBD.

Finally, as the re-organisation of ECCO commences, focusing on the enhancement of individual participation, we reconfirm our desire to widen its implementation in Portugal and attract further participation of Portuguese physicians in its scientific activities.

Francisco Portela, Fernando Magro

Romania



The Romanian story



Faculty of the 9th ECCO Educational Workshop, Cluj, 2009

It began in Innsbruck in 2007, a marvelous Austrian winter. I was there with Prof. Pascu, the President of the Romanian Society of Digestive Endoscopy. At the end of 2006 during the first meeting of the National Romanian Interest Group in Inflammatory Bowel Disease it has been decided to organise our own national society for IBD. We brought with us the Official Letter of Affiliation of our structure to ECCO signed by Prof. Carol Stanciu, the President of the Romanian Society of Gastroenterology

and Hepatology, Prof. Oliviu Pascu, President of SRED and myself as President of the Organising Committee of the soon-to-be-born association. Romania is an Eastern European country with about 22 million inhabitants. There are some 200 to 300 gastroenterologists and around 300 internists with a special interest in digestive diseases. There are six university centres and four other faculties of medicine. In addition, there are ten towns with their own gastroenterology departments and three centres with more

than three endoscopy labs (> 10 in Bucharest), eight centres with skilled colonoscopists and more than 40 other colonoscopy labs in other towns. Even though there has been interest in IBD since the early 70's, we still considered that Romania was a country with a low incidence and prevalence of both Ulcerative Colitis and Crohn's Disease as was shown in the 2002 epidemiology study.

The way ECCO was organised and the success of the Innsbruck meeting encouraged us to continue to design a National organisation for IBD. In autumn of 2007, at the next meeting of our Organising Committee armed with the report of our participation at the ECCO Congress we named the new association "Romanian Crohn's and Colitis Club" (RCCC). The ECCO Congress in Lyon in 2008 encouraged us to continue our efforts and also to study the epidemiological trends in IBD in Romania. New trials were designed which reported an increase of Crohn's Disease cases and an increasing number of difficult to treat patients. The first patients were started on biologicals at this time.

Our personal contacts and the friendship with the ECCO Governing Board helped us to organise an ECCO Educational Workshop before our National Congress of Gastroenterology and Hepatology in Cluj in 2009. Simon Travis and Matthieu Allez came to Romania. The meeting was a great success and in autumn we held our first national meeting on IBD organised by the RCCC to establish definite targets for the next year's second congress. Once again at the ECCO Congress in Prague in 2010, our friends from the ECCO Governing Board agreed to come to Romania for our second meeting. Daan Hommes, Matthieu Allez, Herbert Tilg and Yehuda Chowers came to Mamaia in September 2010 for our national conference on IBD and helped us to have an extraordinary successful meeting.

That's why building our own society and increasing interest in IBD in Romania was made together with our participation to what is now considered by us as a big European family – ECCO.

Mircea Diculescu

Russia



The Russian IBD Study Group



Faculty of the 11th ECCO Educational Workshop, Moscow, 2009

The Russian IBD Study Group (IBDSG) was established in 2002. At the current time, 112 members are actively participating in the group's activities: Leading IBD experts and scientists from Moscow, St. Petersburg and other regions of Russia, as well as practitioners interested in IBD. In 2006 Russian IBDSG, represented by Prof. Elena Belousova and Prof. Alexander Potapov, joined ECCO. In 2010, ECCO counted 12 members from Russia; in 2011 about 15 doctors are going to be ECCO Members. The

Russian IBDSG meeting usually takes place in St. Petersburg every year in May.

During the past ten years the prevalence and incidence of IBD in Russia has increased significantly. As a result, the main goals of IBDSG were to study epidemiology and to create regional registers of IBD patients. As a result of the support from ECCO, particularly of EpiCom and Pia Munkholm, Russia was included in the international project "Is there a West-East gradient in IBD incidence?". The methodical help

of EpiCom facilitated a national epidemiologic study in 22 regions of Russia, which will be finished in 2011.

The absence of national standards for diagnosis and treatment of IBD patients was one of the major problems in Russia. ECCO Guidelines on the diagnosis and management of Crohn's Disease and Ulcerative Colitis were translated into Russian and the majority of physicians now use it in their every day work. In 2009, the Russian IBD SG developed national recommendations on the basis of the ECCO Guidelines, which had to be adapted according to the peculiarities of Russian Health Care law. These recommendations were accepted by the Russian Ministry of Health. Hopefully, this will lead to an increase in state funding for IBD patients in the near future.

Russian scientists Elena Belousova and Inna Nikulina were involved in the working group that developed the ECCO Consensus on "IBD patients' need in the Health Quality of Care". This aspect of the problem was new for Russia. ECCO especially helped the Russian IBD SG to pay attention to the importance of Health Authorities in this field, particularly to the importance of an IBD nurses network.

Another important mission of the Russian IBD Group is to improve the training of practitioners in IBD. In this regard, Russia hosted the 11th ECCO Educational Workshop in Moscow in 2009. Moreover IBD schools for doctors were arranged in Moscow, St. Petersburg, Irkutsk and other Russian cities. Since 2008, IBD SG organises two-day international postgraduate educational courses. From the beginning ECCO representatives (P. Munkholm, B. Vucelić, W. Reinisch, S. Travis, M. Elkjær) were kind enough to take part in these meetings and provided very interesting and important lectures. In May 2010, in Moscow, a conference was held on the worldwide day of IBD, established by the World Organization of Gastroenterology.

We want to thank ECCO for all the help and support during the past few years. We are looking forward to a close relationship and collaboration of the Russian IBD SG and ECCO also in future. We really hope that this link will continue and grow, which is undoubtedly important and beneficial to both organisations.

Elena Belousova, Alexander Potapov

Serbia



Salute from Serbia: What ECCO has meant to us?



Faculty of the 12th ECCO Educational Workshop, Belgrade, 2009

Dear Friends,

Let us begin with the proverb we think of when we wish to describe our friends at ECCO:

"All the grandeur in the world is not to be compared to a good friend." – Voltaire

Here in Serbia we regard ECCO above all as our honest friends and selfless partners who have always strived to perfect medical research and treatment within the field of IBD in Europe.

One may accidentally interpret ECCO as "echo." This, in fact, is not far from truth. The good word about the European Crohn's and Colitis Organisation spreads throughout Europe like an echo, and it finally arrived in Serbia a few years ago. There is so much in Serbia that yearns for reform, and it is us, the physicians who treat these diseases, who know that best. We are therefore extremely grateful to our colleagues at ECCO for providing us with help and guidance along the way to well-established rules,

processes and algorithms which will maximise our efficiency in treating this disease.

New ECCO Members from Serbia are constantly increasing in number, which is evidence enough of the dedication and hard work of ECCO's leadership. Not only do annual panels see steady increases in participation rates, but we can also note that they increase in quality. It is especially pleasing to see our young colleagues being able to acquire appropriate education early on. Thanks to ECCO, they can now learn about proper treatment methods, and meet the world's leading authorities in the field. Most notably, workshop panels and hands-on learning through concrete examples represent some of the best ways of educating the younger generation since they are able to discuss all details and uncertainties they might hold with our senior colleagues, who selflessly share their vast knowledge.

Such competence and leadership guarantee further development and expansion of the organisation to other European countries. This is bound to deepen the relationships and cooperation among doctors and raise the quality of medical treatment, which holds special importance to developing countries such as Serbia, and we shall support the aspirations of our neighbours to join one of Europe's finest medical institutions.

We wish to thank our colleagues again for supporting our efforts to join ECCO, and to send you all our most solemn blessings of good health. We anxiously look forward to many more good years of working successfully together.

Njegica Jojic, Dino Tarabar

Slovakia



What has ECCO meant to us?

It was the year 2002 when a group of doctors (M. Greguš, M. Huorka, M. Kaščák) decided to organise the first dedicated Inflammatory Bowel Disease Day in Nitra. During this meeting we received first information about doctors of various countries grouping together to form ECCO. We were keen to participate and therefore we contacted Prof. Milan Lukáš, the representative of the Czech Working Group within ECCO. This resulted in the organisation of the Slovak-Czech joint event named IBD Day. The willingness and help from Prof. Milan Lukáš was amazing and he has supported us throughout the ten years of our existence and is still always available for special advice.

In 2003, based on these events and with support of ECCO's attributes of friendship and interest, the working group for IBD of the Slovak Society of Gastroenterology was created. ECCO, its ideas and thoughts helped us to organise our working group and in the year 2004, the Slovak Working Group for IBD became a member of ECCO.

The first meetings with Geert D'Haens and Walter Reinisch were really open, frank and

very friendly, potentiated by the fact that Prof. Walter Reinisch accepted our invitation to the IBD Symposium during the Congress of Gastroenterology in the High Tatras. The regular participation of Prof. Laszlo Peter Lakatoš in the Slovak-Czech Day of Gastroenterology in Nitra also proves this support.

What I appreciate most of all is the fact that ECCO shows a permanent interest in development of cooperation with national working groups, which is highlighted by ECCO's effort to integrate members of national working groups into its activities.

By creating professional guidelines, ECCO helped us to form our diagnostic and treatment protocols and thus gave us strong arguments when dealing with representatives of health insurance companies as well as with the Ministry of Health.

Thanks to ECCO even such small countries like the Slovak Republic managed to find their place in Europe and to transform the latest knowledge in medicine, in the field of IBD.

Miloš Greguš

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GETECCU and ECCO: A brief historical note



Alumni and teachers at the course for residents, 2005

When one reads reviews on IBD's epidemiology, it is rather common – even today – to find the sentence: “The prevalence of IBD in Europe shows a clear North-South gradient”. This may have been true until 1980. In fact, IBD was considered “rare” in many hospitals in Spain during these years, and a resident diagnosing Crohn's Disease was always questioned by the

staff: “Are you sure?”. However, the scenario has changed, and it has changed a lot in a very short time. By 1988 several reviews and case-series on IBD had been published and personal interest in IBD appeared in various hospitals starting to collaborate in international groups, especially in epidemiology. A small meeting was held in Valencia on December 20, 1988. During this

meeting, Antoni Obrador gave a lecture on IBD treatment. In another small meeting (22 participants) in Madrid, on February 10, 1990, the idea of an "independent working group to investigate IBD" was launched and two key decisions taken: Miquel Gassull was appointed as Chairman and the group was called "GETECCU". We all had the subjective feeling that IBD incidence was rapidly increasing, as several fine epidemiological studies confirmed years later; and so created GETECCU which stands for "Grupo Español de Trabajo sobre Enfermedad de Crohn y Colitis Ulcerosa" (Working Group on Crohn's Disease and Ulcerative Colitis). We chose the name very carefully, by using "trabajo" (work) as a preeminent word in our name. We started working. The first open national meeting was held in Zaragoza on April 27, 1990 where original work from 15 small emergent groups with special interest in epidemiology, pathophysiology, diagnosis and treatment of IBD was presented, with a special lecture given by Salvador Peñan. After that, we initiated yearly working meetings, always in the first days of October, with 20 to 30 people coming at first and more than 400 people attending the meeting in 2010.

A first Spanish book by Luis Abreu and César Chantar was published in 1991; followed by the first multiauthored textbook from GETECCU, edited by Miquel Gassull, Antoni Obrador and César Chantar with 45 different authors (23 from Spain, 21 from other European countries and one from Canada) that was published in 1994 both in Spanish and English. Two more editions have followed, and the third is being used as a reference text in Spain. However, this endeavour has been possible only thanks to the generous contribution of our friends from all over the world. Unfortunately, this textbook is impractical for daily use, and so Joaquín Hinojosa and Pilar Nos from Valencia, developed a pocket manual

that is of common use by residents, staff members, and by some of our ibero-american colleagues. A fifth edition will appear later this year. Books are basic, but slow. So, GETECCU also introduced a journal, "Enfermedad Inflamatoria al Día", which periodically (four times a year) gives updates on IBD. 2,000 copies are printed of each issue and it is also freely available on the website of GETECCU (www.geteccu.org).

Educational meetings and courses for gastroenterologists, internists, and even family physicians have been organised by GETECCU throughout the last 20 years, and several hundreds of assistants have had the opportunity to improve their knowledge on IBD. We also developed a very special programme for residents just ten years ago, starting in May 2000. This intensive and very interactive course is repeated two times a year, and more than 400 of them have attended to be trained there. Some of the early pupils are now teachers in the course and serve in the Boards of GETECCU. This course was in fact the model for the ECCO Course for young gastroenterologists. Some of them grouped together and founded the "GETECCU YOUNG GROUP", a group of young IBD specialists working in some educational and investigation projects and developing a very interactive meeting twice a year.

Of course, the "raison d'être" of a scientific society is the advancement of science. GETECCU has promoted several studies, including randomised clinical trials, which have been published in Gut, the Journal of Crohn's and Colitis, the American Journal of Gastroenterology as well as within Alimentary Pharmacology and Therapeutics and other prestigious journals. Currently, we have several clinical trials at national and international level ongoing. Every year, GETECCU offers investigational grants to support one basic and one clinical project, and every two years a special grant for an epidemiological study. There

are a number of projects ongoing, and some of them are based on cooperative effort of more than 40 centres, working on a clinical database called "ENEIDA", which, by now, contains data up to 14,000 patients. Detailed information are available on the associations website.

Our work would not have any sense if we forget our patients. GETECCU has a very special relationship with the Spanish group of patients, which for many years followed the leadership of a Spaniard by election: León Pecasse. ACCU is a federation of local and regional patient associations, and takes different lines of action (www.accuesp.com). GETECCU not only always supports patients and their families but also tries to learn about their needs, problems and expectations: The key concept of IBD cannot be grasped without the patient's perspective.

To undertake all these activities, GETECCU is not alone. GETECCU is one (and the largest) among six working groups of AEG (Spanish Association of Gastroenterology, www.aegastro.es), with a key contribution to the annual AEG scientific meeting. In addition, GETECCU is a very active member of ECCO: A high percentage of the last year's abstracts were submitted by Spanish delegates and Spaniards were the second largest national group of participants at the ECCO Congress. Some of us (M. Gassull, E. Cabré, J. Panés, M. Sans and E. Doménech for instance) have in the past and are still contributing to the work of some ECCO Committees and/or projects.

We cannot forget the pharmaceutical industry in all these developments. Most of our activities are possible only by their financial and logistical support. From the start, this collaboration has been on the basis of absolute scientific and educational independence. GETECCU has thus maintained absolute (although sometimes it has not been easy) control of the contents of publications, meeting programmes, and grants through the years.

We were a group of no more than 22 people about 21 years ago; now we are more than 450 paying members. We have done many things, but we are always ready to start new and exciting times. We realise that in these "global" and multicultural era, Europe is our real nation; if we want to maintain leadership we have to work together. The engagement of GETECCU with ECCO does exist; it is very strong and will be the motor for our future.

Fernando Gomollón, Joaquín Hinojosa

Switzerland



Happy birthday ECCO from your Swiss friends

ECCO was founded at the same time that Swiss gastroenterologists who were interested in IBD started to meet on a regular basis. This national platform, called IBDnet had the goal of education in IBD and of promoting IBD research within the country. When we heard of ECCO we were very happy to see that the interest in IBD was not limited to our small country but extended to a European level. ECCO interestingly did not stop at the official borders of the European Union. It took several decades to create the EU. ECCO however, was able to integrate within a few years several countries, some of them in the North and the East that probably will not join the EU within the next 50 years.

In Switzerland we invited foreign ECCO Members to give talks at our national gastroenterology meetings. Especially, the ECCO Congresses were a highlight for most of the Swiss participants.

Many relationships were built that finally ended in scientific collaborations. One of the European research projects (IBDase) that was managed from Switzerland received support from ECCO. Furthermore, the establishment of the Swiss IBD cohort study was supported by the ECCO Members in their function as external advisors. Looking back over ten years, I have the impression that European GI doctors have developed a keen energy around IBD and that the foundation of ECCO has played a key role for European IBD scientists in being able to compete with their colleagues of North America. We hope that this tremendous development will continue and will finally lead to an improvement of the quality of life of our IBD patients.

Frank Seibold

Ukraine



One of the youngest ECCO Members



Faculty of the 14th ECCO Educational Workshop, Donetsk, 2010

Ukraine has been an official member of the European Crohn's and Colitis Organisation since 2008. Ukrainian membership in ECCO was approved and supported by the Ukrainian Gastroenterological Association (UGA). National representatives of Ukraine were elected at the UGA meeting and Ukraine became a full-fledged member of ECCO. The target of Ukrainian participation in ECCO is the implementation of the ECCO Guidelines and recommendations in routine medical practice. It should be noted that after our ECCO Membership

commenced, on the platform of the Ukrainian Gastroenterological Association in Kiev in 2009, an Inflammatory Bowel Diseases (IBD) working group was created. This group consists of leading specialists of the six main IBD centers of Ukraine. Besides scientific IBD research, the group has already set up a registry of IBD patients in Ukraine.

Another role of the IBD working group is education and the development of educational programmes. On September 17, 2010 the 14th ECCO Educational Workshop took place in

Donetsk. During this meeting, interest in IBD problems united not only gastroenterologists but also coloproctologists as the Association of Coloproctologists of Ukraine selected participants of the IBD working group.

In 2010, 12 new Ukrainian delegates became individual members of ECCO. Also in 2010, the first edition of the Ukrainian Guidance on the diseases of bowels was published. It is important to stress that the preface to this edition was written by ECCO President Prof. Daan Hommes as well as by the ECCO representative in the Scientific Committee of UEGF, Prof. Yehuda Chowers. The book has received high recognition not only in Ukraine but also abroad and was distributed in Russia, Belarus, Moldova, Kazakhstan and Uzbekistan. Our participation in ECCO aims to improve scientific knowledge about IBD and to increase the quality of diagnostics and treatment of IBD patients within the Ukraine.

Andrey Dorofeyev, Tatiana Zviagintseva

United Kingdom



A reflection on our interaction with ECCO



From the shores of Britain –
looking to the future horizon

Within the United Kingdom there are 1,050 consultant gastroenterologists, 350 non consultant career grade gastroenterologists, 795 gastroenterology trainees and 210 clinical nurse specialists. The majority are members of the British Society of Gastroenterology, an organisation focused on the promotion of our speciality throughout the United Kingdom. Over

the last ten years Inflammatory Bowel Disease has evolved as a clinical sub-specialist interest for many working in the United Kingdom, such that the IBD section of the BSG has over 850 members. National standards for the care of patients with IBD (www.ibdstandards.org.uk) have been developed by key stakeholders including the UK patient association Crohn's and Colitis UK (formerly NACC) and were launched in 2009. UK academics are active in IBD research and participate in multiple national and international clinical and scientific collaborations. Finally the last decade has witnessed the evolution of the IBD nurse specialist as an integral part of the multidisciplinary team at over 60% hospitals (UK IBD audit 2008).

ECCO has been a key partner for the UK in the recognition of IBD as a specialty in itself, alongside the development of IBD services, research and education. UK gastroenterologists are the second largest group of ECCO Members and have served in many key roles within the organisational structure as it has developed. Indeed we are proud to provide the President-Elect! We have benefited enormously from the annual congresses and make up a significant proportion of the delegates each year. Our trainees support and benefit from the activities of Y-ECCO, and UK IBD nurses have been pivotal in the formation and development of N-ECCO and the annual activities of N-ECCO. Along with our colleagues from across Europe we have debated the optimal management of patients with IBD by participating in the consensus process. The output from this has in turn been an invaluable tool to support change in the

national guidelines for the use of biological therapies published by the National Institute for Clinical Excellence (NICE).

UK IBD specialists will continue to support ECCO as it grows within the new organisational structure over the next decade. We will enjoy sharing best clinical practice, collaborating in clinical/scientific research and delivering evidence based education with our colleagues across Europe!

James Lindsay, Tim Orchard

ECCO and improved IBD practice throughout Europe:

The work of ECCO EduCom

In March 2002, the late Antoni Obrador hosted the first formal meeting of the ECCO Governing Board in Palma de Mallorca. On that occasion, the discussion focused on the possible activities that ECCO could organise outside its regular meetings that, at that time, only took place during the annual UEGW. The initial proposals were for ECCO-driven studies or clinical trials, but the challenge of launching coordinated clinical activities was felt too high for such a young organisation. In contrast, with the surge of basic scientific advances and the advent of biological therapies, independent, balanced and high quality education was felt by the group to be an as yet unaddressed need. Education would have the potential to improve the care of IBD patients throughout Europe and the idea that ECCO could contribute to this goal was well received by the group.

The ECCO Course

The history of the ECCO Course has been written by Miquel Gassull in this book. In Dublin in 2011, the 9th edition of the ECCO Course, by its complete name “The ECCO Intensive Clinical Course on IBD for residents, fellows and junior gastroenterologists” will take place. The course is now endorsed by UEGF, with an educational grant for monothematic initiatives, awarded for 2009 and renewed this year. The course organisation is very professionally run by the ECCO Office in Vienna, and the faculty



Template of the first ECCO Course diploma, 2003

is still very motivated. Having been one of the course directors for the first eight editions, I have been amazed how many of the teachers would regularly remind me “not to forget them for the next ECCO Course”. The course has of course evolved, thanks to the input of the teachers and the students, to become the “ECCO School” that Boris Vucelić had in mind to create in Europe. Indeed, the course is not only the oldest continuous activity of ECCO, but it has fostered many scientific interactions and collaborations, offered training opportunities for fellows, and contributed to strive for excellence among young IBD scientists. The course has also triggered the launch of Y-ECCO, which was initially created by alumni of the course who wanted to keep alive the positive spirit they experienced, after the course finished. On the ECCO website, one can find all the yearly lists of the course participants. Reading them as part of the preparation of this chapter, I was amazed

how many of those students have become respected scientists and/or clinicians in the field of IBD. It may have happened independent of their participation in the course, but they all elected to take it during their training, a nice testimony of interest for the educational work of ECCO.

The ECCO Educational Workshops

When the first European evidence-based consensus conference on the diagnosis and management of Crohn's Disease was published by ECCO in 2006, Boris Vucelić voiced and circulated his idea of using the consensus material, in particular the statements, as teaching material to be combined with clinical cases. His idea was a response to the issue of publicising and implementing the first ECCO Guidelines, a great achievement for ECCO, but which was at risk of being not more than "yet another consensus paper". Boris' idea was to create a collection of clinical cases designed to illustrate sets of ECCO Statements and to use them in various combinations, to provide continuous medical education in the different ECCO Country Members, with the help of local organisers and ECCO National Representatives. Such sessions would be lively and informative for gastroenterologists interested in IBD, while positive for ECCO in its endeavour to implement its statements and more generally its views about the quality of care for patients with IBD. The advantage of a central collection of clinical cases produced by ECCO EduCom would be that the same messages would be forwarded at each conference, regardless of the presenter of the cases. This was a useful feature, because Boris wanted to organise what would become known as the "ECCO Educational Workshops" to

a series of events. Boris presented the project to the EduCom, Gert van Assche, Paolo Gionchetti and other members of ECCO volunteered cases, which were then discussed and finalised.

As a pilot for this novel activity, the home town of Boris Vucelić was chosen, and the 1st Educational Workshop: "Implementation of ECCO Consensus on Crohn's Disease and Ulcerative Colitis" took place in the Hotel International, Zagreb on November 10, 2007. There were 61 participants from five countries: Croatia (36), Bosnia Herzegovina (12), Serbia (10), Bulgaria (2) and Slovenia (1). To increase the interactions, the teaching faculty of the workshops has been set to include local academic gastroenterologists, ECCO National Representatives, and members of the EduCom, SciCom and Governing Board, to represent ECCO. In Zagreb, representatives of ECCO were Philippe Marteau (France), Peter Lakatos (Hungary), Boris Vucelić (Croatia) and I, with the administrative help provided by Nicole Eichinger. Based on the on-site experience from the faculty as well as from the feedback from the participants, the workshop was perceived as very interactive and lively, so participants enjoyed it.



Flyer of 1st ECCO Educational Workshop, Zagreb, 2007

After a second workshop the same year in Austria, which failed to attract a large crowd for several reasons, including the competition for other activities at the same time in Vienna, the workshop series took a regular pace. At the present time, 18 workshops were successfully organised. The 16th ECCO Educational Workshop, which took place in Riga on October 9, 2010, received endorsement by UEGF, in the form of an educational grant. A working group from EduCom, chaired by Gerassimos Mantzaris and Rami Eliakim, is constantly working on the update of the cases and to develop the programme. For the first time in 2010, a workshop was also organised outside of Europe, in São Paulo, Brazil.

Personal perspective

The opportunity offered to me to participate actively from the onset in the creation and the initiation of ECCO EduCom activities such as the course and the workshops has been a wonderfully stimulating adventure. With my fellow members of EduCom, through our commitment and the programmes we proposed to students and fellow gastroenterologists from all over Europe, we saw the emergence of a spirit of excellence in education, aimed at contributing to the ultimate goal of ECCO: To provide better care for IBD patients throughout Europe. These educational activities, which integrated themselves in all the other projects and programmes of the various committees, helped ECCO to become a central institution in the field of IBD, respected far beyond the borders of Europe. This superb adventure will continue. At the time of this first 10 year anniversary, I take this opportunity to thank all the colleagues, students, ECCO Officers and the many others that spent time and energy to make all the EduCom projects so successful.

Pierre Michetti

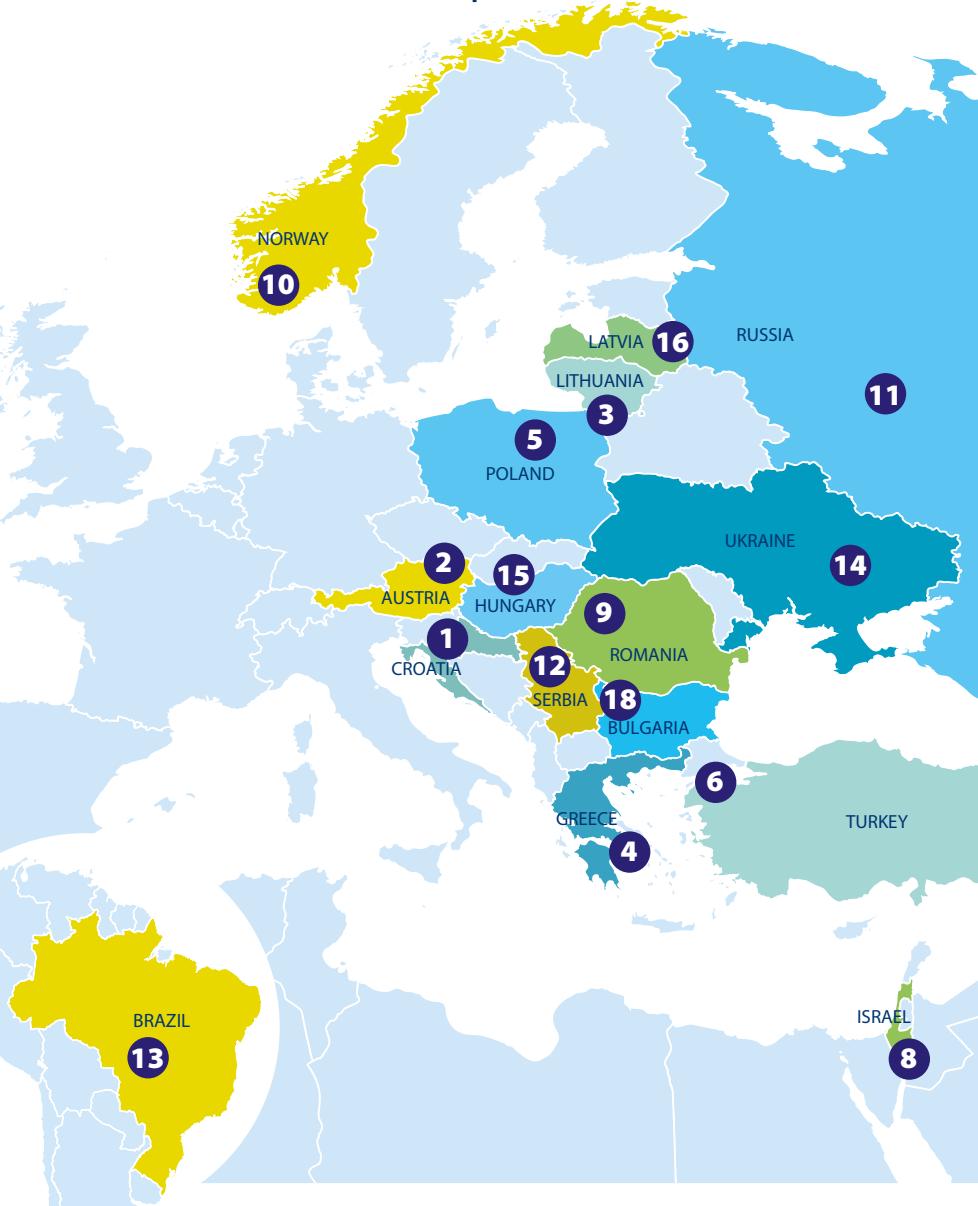
-  **1st ECCO Workshop**
Zagreb, **Croatia** - November 10, 2007
-  **2nd ECCO Workshop**
Vienna, **Austria** - December 15, 2007
-  **3rd ECCO Workshop**
Kaunas, **Lithuania** - May 10, 2008
-  **4th ECCO Workshop**
Athens, **Greece** - September 13, 2008
-  **5th ECCO Workshop**
Warsaw, **Poland** - September 26, 2008
-  **6th ECCO Workshop**
Istanbul, **Turkey** - November 8, 2008
-  **7th ECCO Workshop**
Oporto, **Portugal** - November 15, 2008
-  **8th ECCO Workshop**
Haifa, **Israel** - May 5th, 2009
-  **9th ECCO Workshop**
Cluj Napoca, **Romania** - June 17, 2009
-  **10th ECCO Workshop**
Oslo, **Norway** - September 4, 2009
-  **11th ECCO Workshop**
Moscow, **Russia** - September 17, 2009
-  **12th ECCO Workshop**
Belgrade, **Serbia** - October 14, 2009
-  **13th ECCO Workshop**
Sao Paulo, **Brazil** - June 19, 2010
-  **14th ECCO Workshop**
Donetsk, **Ukraine** - September 17, 2010
-  **15th ECCO Workshop**
Budapest, **Hungary** - September 18, 2010
-  **16th ECCO Workshop**
Riga, **Latvia** - October 9, 2010
-  **17th ECCO Workshop**
Galway, **Ireland** - October 15, 2010
-  **18th ECCO Workshop**
Sofia, **Bulgaria** - November 11, 2010



PORTUGAL



ECCO Educational Workshops – Where ECCO has been so far



ECCO and UEGF

The United European Gastroenterology Federation (UEGF) was founded in 1992 as a non-profit medical federation to provide a framework to Europe's leading societies with an interest in diseases of the digestive system.

UEGF now embraces 16 member societies and its annual United European Gastroenterology Week hosts a congress of up to 14,000 participants from over 100 different nations.

From its very beginning, ECCO had a major interest in building tight links with UEGF and participating in its activities. Due to their existing involvement in UEGF Renzo Caprilli, Miquel Gassull and Boris Vucelić posed as ECCO's principal initial contacts, to establish the basis for ECCO's acceptance as an Associate Member of UEGF in early 2001. Since then there has been fruitful collaboration between the Federation and our Organisation.



Renzo Caprilli, Boris Vucelić, Pierre Michetti and Miquel Gassull



Walter Reinisch, UEGW Barcelona 2010

As a first step Geert D'Haens joined the Scientific Committee of UEGF as official ECCO representative, to assist in crafting the scientific programme for UEGW in Prague 2004 and Copenhagen 2005. All societies that make up UEGF have representation in this committee, to guarantee a comprehensive and balanced programme which addresses

clinicians, academics and basic scientists alike. ECCO's particular part in the Scientific Committee is to choose on the up-to-date topics in IBD for the invited lectures and to steer the selection process for oral presentation among the peer-reviewed abstracts submitted under the heading IBD for UEGW.

Congress	Accepted as Orals	Submitted IBD abstracts
UEGW Barcelona 2010	63	522
UEGW/Gastro London 2009	59	579
UEGW Vienna 2008	68	442
UEGW Paris 2007	50	430

Number of UEGW abstracts related to IBD and accepted as oral presentations

In 2005 I followed Geert into UEGF's Scientific Committee where I was active until 2008 and where I contributed to the programmes for UEGW in Berlin 2006, in Paris 2007 and in Vienna 2008. From 2006 onwards, I was further supported by Séverine Vermeire who was appointed as independent member of the Scientific Committee. In Vienna the

UEGF organised for the first time a two-day postgraduate course by comprehensively incorporating endoscopy, liver and general gastroenterology. IBD was highly regarded in the course programme. Yehuda Chowers replaced me in the Scientific Committee in 2009 and will be active in this function until 2012.



Jean-Frédéric Colombel with the UEGF Research Prize, London, 2009

The programmes on IBD at UEGW London 2009 and Barcelona 2010 visibly reflect their views on relevant topics in the field.

Over the last years we have seen a growing number of abstracts related to IBD submitted to UEGW which plateaued most recently in Barcelona 2010. Up to 10% of these abstracts are accepted as oral presentations having reached the top in Vienna 2008. Recently, all sessions on IBD have been among the top three attended within UEGW.

Since 2008 UEGF has awarded an annual research prize of EUR 100,000 to support outstanding research projects in European gastroenterology. The UEGF Scientific Committee uses a transparent selection process to identify the best candidate. The first UEGF Research Prize was awarded to Prof. Markus Neurath in 2008 for his project on molecular imaging of the intestinal immune system in IBD, followed by Prof. Jean-Frédéric Colombel in 2009. Remarkably, Jean-Frédéric Colombel submitted a project on behalf of ECCO incorporating ECCO's scientific network (for ORIGIN: Observing Relatives, Immunity, Genetics and the microbiome before the onset of Crohn's disease).

John Atherton, Head of UEGF's Scientific Committee congratulates ECCO on its 10th birthday: *"Youth is good, and ECCO representatives (and IBD independent members) on the UEGF Scientific Committee have been young, vibrant and full of the best ideas. Many of the most imaginative innovations at UEGW have come from you, and this has contributed massively to the success of UEGW. Thanks so much – and good luck with the teenage years!"*

Like to the Scientific Committee of UEGF, the Education Committee and more recently established Future Trends Committee of UEGF

are created by representatives of all societies under its umbrella. The UEGF Education Committee ensures continuing education on all new developments related to digestive diseases to health care practitioners, by providing, in addition to UEGW, multidisciplinary postgraduate courses in gastroenterology, liver diseases and endoscopy. ECCO's involvement in this committee started in 2008 with Boris Vucelić aboard. ECCO takes advantage of initiatives of UEGF which offers financial support for educational activities of its member societies. In this regard, ECCO is receiving support for its IBD Courses in 2010, 2011, 2012 as well as for the ECCO Educational Workshops in Serbia (2009) and Latvia (2010).

Pierre Michetti is the representative of ECCO in the youngest UEGF Committee, the Future Trends Committee which started its work in 2010. The purpose of the committee is to assess the impact of emerging trends in research, clinical practice and scientific-technological developments of UEGF and its members and to advise on steps to be taken.

Finally, the Public Affairs Committee (PAC) of UEGF promotes awareness of digestive diseases in Europe and helps to increase the understanding of gastroenterology on a public and political level. Very successfully, PAC interacts with European decision makers in health policy to impact European-wide health plans related to gastroenterology. Initially as independent member (2006-2009) but since 2009 as representative of the Medical Block, Miquel Gassull is part of PAC. I joined PAC as independent member in 2010.

In summary, the collaboration between UEGF and ECCO has ripened to a fruitful friendship, which could not be better expressed than by quotes from UEGF's President-Elect Colm



Miquel Gassull and Colm O'Morain at UEGW Barcelona 2010: "Fun Run" against Colon Cancer

O'Morain and President Rolf Hultcrantz.

Colm O'Morain: *"I am delighted that ECCO has now matured and is well established. It is an essential component of UEGF. It embodies the philosophy of a federation in its multidisciplinary approach to treating patients. It is to be congratulated on involving key stakeholders including young trainees, nurses and patients, and their philosophy of delivering a patient-centred service. I have a close affinity to ECCO and consider it my constituency. All my research life has been devoted to IBD. ECCO has been integral in our common interests. I have been involved with ECCO since its foundation. I look forward to continuing to work closely with ECCO during my presidency and look forward to its further growth."*

Rolf Hultcrantz: *"ECCO is certainly a unique organisation not only in Europe but also in the world. Through your active scientific and educational efforts you have improved the situation for many patients with Inflammatory Bowel Disease. ECCO has also emerged as one of the major contributors to the work and success of UEGF both during the UEGW and in other activities. UEGF would not be as successful without ECCO, and we are most grateful! UEGF wishes ECCO many happy returns on your 10th birthday and we are sure that a great future lies ahead for you."*

Walter Reinisch

Y-ECCO:

Assuring the future

Those days in Amsterdam

The classroom was full of students a little bit tired of all the information they had received that morning. The 4th ECCO IBD Course had started. Daan Hommes thought to take a final break by organising a funny quiz about IBD. Everybody had a green and a red card and we had to raise the right one at each question. One wrong answer and you were out. I remained in the game until the end with another guy (I don't remember who).

Daan Hommes asked the last question: *"Which number am I thinking of?"* My colleague said: *"Four"*, I answered randomly: *"Seven"*; Daan said to me: *"You won the game!"*. Then I got a black umbrella with the Rembrandt's *"Nachtwacht"* painted on it. It was my good-luck charm for the great adventure that was just starting.

When I came back to the hotel, I started to read *"The history of ECCO"* by Renzo Caprilli. The incredible story he told made me proud to participate in the ECCO IBD Course, and I said

to myself: *"It should be great for me to be active in ECCO, but how?"*. With this thought in my mind, I went out for dinner. Some of the participants had organised a friendly dinner in the centre of Amsterdam. We went to an Indian Restaurant near the Dam and, while we were talking, there came the idea to build up a network in order to keep in touch after the course. This informal network would be able to let us meet during future congresses, collaborate for future activities or create an exchange between young fellows. This idea circulated between



ECCO Course participants after dinner in Amsterdam, 2006

the attendants and the day after, during the final dinner at Vijf Vlieghe, we exchanged our contacts to start with this network. Nobody could realise, at that time that Y-ECCO had been conceived.

The birth of Y-ECCO

Some day after the course, I went into Professor Caprilli's office. He asked me how the course had gone and I answered that it was a great experience and that we had created a mailing list of young fellows to keep in touch; he said: *"That's great! You should create a sort of junior club inside ECCO. You should write to them and ask if they are interested in this initiative."* I did that and the feedback was very positive. We soon started to collect some ideas on how this "club" could start and I tried to enlarge our group thinking to contact also other people attending the ECCO IBD Courses in previous years.

In July 2006, Prof. Caprilli came back from the ECCO Governing Board meeting and he told me that ECCO was enthusiastic about welcoming a young investigators' group; then he asked me to continue with our initiative in order to present this new group during the next ECCO General Assembly at UEGW Berlin 2006. At that time, I realised that a mail exchange was not enough to discuss the main topics. We needed another way to meet. I tried to do that by a common chat room (Windows Live™ Messenger) on the internet, in order to create a sort of live session in which we could meet and discuss. We started with five participants: Marc Ferrante, Maia Boscà, Kostas Katsanos, Andrea Cassinotti and me. Unfortunately, Paul Fortun, Alan Schopfer, Daniela Bojic and others were not able to participate and gave their contribution afterwards by e-mail only.

The idea was to create a sort of ECCO "nursery" in which young people could familiarise with all the ECCO activities: Scientific projects, educational activities and exchange programmes. Somebody thought to organise the activities creating a sort of statute (we called it "inner rulement") and some figures that could coordinate everything. This idea unfortunately led to big misunderstandings within ECCO in the following months, because it looked like an "alternative" ECCO, which was never our aim. We discussed possible goals and projects that our group might develop. Every idea was collected and discussed as we prepared for our first meeting in Berlin, where we were going to elect the first chair of the group.

After several sessions (some even finished at night), we concluded that our aims were:

- Friendship and cooperation between young doctors and scientists interested in IBD, as a section of ECCO,
- Education: Courses, seminars, meetings, internet, and other instructive material,
- Scientific progress through common interest projects supported by ECCO exchange programmes in the different hospitals of the young ECCO Members,
- Create a new webpage, if possible as a sub-page of the ECCO website, where young investigators can find IBD updates, project information, information about the different exchange hospitals and the on-coming meetings, courses and a chat connection or e-mail to expose doubts.



The first Y-ECCO Meeting, UEGW Berlin 2006

Seven multicentre projects were also presented to be discussed in our first meeting.

I was asked to present the group during the ECCO General Assembly on October 22, 2006. The idea of a young group in the ECCO Family met general consent and was a good predictor for our first meeting the day after.

We met on October 23 in a small room in Berlin. About 30 people were present, including Daan Hommes and Yehuda Chowers. We presented all the topics and discussed how to start with them. Everybody was enthusiastic about the seven studies we had proposed and about the possibility of exchange projects between IBD centres in Europe. Finally, we elected our first Secretary, Marc Ferrante, and we started with the elections of the chair. It was a head-to-head between Paul Fortun and me, and finally I was elected. That evening, an enthusiastic group of young people was born, unanimously called Young ECCO (Y-ECCO). We planned to celebrate the new-born with a glass of champagne, but Kostas Katsanos forgot to bring it (and this event

was included in the report of the meeting).

From this moment on, all people under 35 of age and all the ECCO Course participants were able to join Y-ECCO and the number of subscriptions doubled every year.

Activities of Y-ECCO

Marc and I began quickly to set up all our activities. Our seven proposals for multicentre research projects were reviewed by ourselves using a feasibility form and then sent to the ECCO SciCom for evaluation. Unfortunately, our great expectations suddenly disappeared when the SciCom communicated that all our projects were too ambitious and not feasible, as most of them were prospective interventional studies that required a large amount of money and huge efforts in coordination. This response dampened our enthusiasm for proposing new studies, but some months after we were able to conclude our first collaborative study

proposed by Shomron Ben-Horin on the use of immunosuppressants in IBD and concomitant *Clostridium difficile* infection. Another study involving many young people has also been conducted recently, on the clinical activity of IBD after H1N1 vaccination, lead by Jean-François Rahier.

We also had an idea to start with a European IBD database. We did not know, at the moment, that Walter Reinisch was working on IBDIS. We asked Margarita Elkjaer, a brilliant Danish member of Y-ECCO, expert on the national Danish IBD database, to suggest the best way to start with it. The idea was then discussed with Walter Reinisch during the next Y-ECCO meeting in Innsbruck, in 2007, and we decided not to build a new database, but to work within the IBDIS project. In fact, some Y-ECCO Members have participated in the validation project of IBDIS.

Another idea was to create the opportunity of visiting IBD centres abroad in order to learn some techniques or act as clinical observer. This idea came because, when I was a student in medicine, I spent some time in Paris to learn how to manage gastrointestinal diseases and IBD: That was one of the best experiences in my life and I thought it would be great if ECCO would grant young fellows to go abroad to exchange experience in a sort of ECCO Network of IBD centres. This project was discussed with Daan Hommes and Séverine Vermeire during a small meeting in Amsterdam in 2007 and proposed to SciCom. That year, ECCO started with the Travel Awards and some people have visited other centres in Europe, supported by ECCO.

From the educational point of view, Marc proposed that we organise a Y-ECCO Workshop under the active supervision of EduCom. These workshops (something very different from the ECCO Educational Workshops) would be focused on specific topics, such as presentation skills, how to write a paper, or how to write

a protocol. It would be open to all Y-ECCO Members and all participants of the ECCO IBD Course. The first one was on presentation skills, organised in Lyon during the 3rd Congress of ECCO. It was very well conducted and most of the participants enjoyed it. Other workshops were scheduled during the next ECCO Congresses (Hamburg 2009 and Prague 2010) and were successfully attended.

Y-ECCO in the statutes

Y-ECCO was born at a crucial time in ECCO's history. At that time, ECCO was changing in its own structure and the correct place of Y-ECCO was difficult to find. Since 2007, ECCO tried to find a way of putting the Y-ECCO Structure and activities inside the official statutes. Our initiatives were under the supervision of SciCom and EduCom and sometimes it was difficult to put projects clearly under the umbrella of just one committee. For that reason, in 2007, during the UEGW, Y-ECCO was officially included in the ECCO Statutes as a group of ECCO Members younger than 35. The chair would be one representative of the group and Y-ECCO activities would be presented every year to the Governing Board. Chairs would be replaced every two years. In both SciCom and EduCom, Y-ECCO got one representative, which were Silvio Danese and Charlie Lees respectively.

The re-organisation of the ECCO Structure in 2010 has brought further changes for Y-ECCO, which now sits on the Operational Board.

Conclusion

Y-ECCO was the first "subgroup" of ECCO, now opened to N-ECCO, S-ECCO and P-ECCO. It arose spontaneously from the ECCO IBD School in



The past and the current Y-ECCO Chair (Gionata Fiorino and Marc Ferrante), Hamburg, 2009

Amsterdam, because we young investigators wished to become an active part of this great family. Some misunderstandings and many challenges occurred during those years, but the results of our efforts and our hard work are greater than expected. I stopped being chair in 2009 and left my task to Marc Ferrante, who is a brilliant guy that shares with me the spirit of Y-ECCO.

In many sports, the best teams get their success if they are able to find good young players who can grow with the team, until they are ready for the biggest competitions. From my point of view, Y-ECCO is the breeding ground where members can grow and get their experience in order to lead ECCO in the future. On the other hand, Y-ECCO gives young people all facilities to enter in this great family and easily contribute. All

the aims we planned in 2006 have been reached and much more: Together with Travel Awards and Y-ECCO Workshop, we have a webpage on the ECCO website, a page in the societies magazine ECCO News and our group is strongly included in the structure of ECCO. In addition, Y-ECCO Members also chair scientific sessions at the annual ECCO Congress and participate in the ECCO IBD Course. Some collaborative studies have been concluded successfully. Anyway, the achievement of these goals is only the starting point of further projects. Nobody should forget the two keywords of the group, which summarise the real spirit of Y-ECCO: Friendship and collaboration. I hope these feelings will always lead Y-ECCO in the future.

Gionata Fiorino

N-ECCO:

Why the nurses joined



N-ECCO Steering Committee at ECCO Congress in Hamburg, 2009

Nurses joined ECCO for the first time in March 2007.

It was in Innsbruck that the first Nurses' Network Meeting was attended by 60 delegates. IBD nurses from Europe wanted to meet and share their experience of caring for patients with IBD.

The main objectives of N-ECCO were and still are to improve professional nurse education in Europe with a particular focus on IBD care and to create networking opportunities. This first meeting, supported by EFCCA and Abbott Pharmaceuticals in particular, was a success.

The second N-ECCO meeting took place in Lyon in February 2008. The response of this

meeting was again positive and the participants were satisfied with the interesting topics, with experienced speakers both nurses and doctors. Areas were identified for improvement such as the need for a syllabus and better communication between the N-ECCO National Representatives. We continued to be aware of the language barriers among the European countries.

Further successful nurse meetings took place in Hamburg in 2009 and in Prague in 2010. The nurses created the term N-ECCO, similar to Y-ECCO, meaning Nurses of ECCO and for the first time there was also a N-ECCO School organised for IBD nurses with a basic IBD programme in Prague, 2010.



N-ECCO Network Meeting at ECCO Congress in Prague, 2010

Thanks to the collaboration of the N-ECCO Steering Committee, the ECCO Office, the ECCO doctors' support, but also certainly not forgetting patient organisations such as EFCCA and the financial support from different pharmaceutical companies, N-ECCO has the opportunity of improving and creating new ideas year by year. We have recently finalised the challenging Dublin programme for both the 5th N-ECCO Network Meeting and the 2nd N-ECCO School.

different profile of nurse specialists in different countries, although the common theme is the patient and how specialist nurses can improve the quality of care.

So far, the N-ECCO train is moving forward and after ten years of ECCO we can be proud of the fantastic work which has been done thanks to the cooperation of so many hard working people.

Patricia Geens

In the future N-ECCO wants to work on the development of IBD nurse guidelines. We plan to create a "handbook" listing required skills for IBD nurses that can be used in different European countries. This has to recognise the



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The ECCO Publications: ECCO News and JCC

During the first years of ECCO surgeons were almost absent in the organisation. Being a colorectal surgeon with a major interest in IBD I became one of the first ECCO National Representatives of Sweden. I do not remember any other surgeons taking an interest until we started on the consensus. Now surgeons are taking part in the ECCO activities in increasing numbers and I hope this will strengthen ECCO and IBD throughout Europe.

However, that's not the story I am here to tell – it's about our publications. My background in this started when I was Chairman of the Swedish Society of Gastroenterology. This society has a long tradition of having a rotation of gastroenterologists and surgeons as Chairmen. The way we kept our members informed of current activities was by distributing a double folded "newsletter" now and then. Not a very good solution and certainly a piece of paper that most members would send to the bin before reading. During that time, however, I was approached by Mediashuset, who offered to provide the Swedish Society with a professional newsletter financed solely by advertisements from the pharmacological industry. This was an immediate success.

The ECCO News

A few years after ECCO was formed, discussion occurred about an ECCO scientific journal. There were different opinions on whether we should create another IBD journal to compete

with the one already in existence. Miquel Gassull was the driving force. However, it took a while before he managed to convince the Governing Board that this was a good idea. With my good experience with Mediashuset and the Swedish journal I had a discussion with Olle Lundblad at Mediashuset whether an ECCO society magazine (ECCO News) might be possible at a European level. Olle immediately took to the idea and I tested it first on Marc Lémann and Jean-Frédéric Colombel at the UEGW Copenhagen 2005. Jean-Frédéric Colombel was at that time not convinced that another scientific journal, as proposed by Miquel Gassull, was the way forward, so he strongly supported the idea of ECCO News. Olle started to think about the practical details involved and came up with the idea that we should have a common text all over Europe, but that advertisements should be acquired nationally. This would reflect local pharmaceutical companies and traditions and be a better way of reaching the necessary financial goals. From the beginning Mediashuset also assured us that they would provide a journalist, removing the burden of having to produce a certain number of pages for each issue. With these plans Olle and I approached Miquel at the first ECCO Congress in Amsterdam in 2006. He was the ECCO President at that time and he was immediately in favour of launching ECCO News.

The aim of the organisation's magazine was discussed at board meetings and we agreed on a format and outlined the contents. I was appointed editor with Peter Lakatos and Milan



Tom Øresland (Editor of ECCO News)

Lukáš as co-editors. The plans were approved and shortly thereafter production started.

The glue that keeps us together

The ambition of ECCO News is to be the glue that keeps us together, to reflect what's going on within the organisation and to report on IBD activities at large within Europe. You are by now aware of the structure. The first page is the message from our President, then the committees have their regular pages. Our senior writer, Per Lundblad (Olle's brother) does a lot of work interviewing key persons within the organisation, but above all writing reports on the ECCO Congresses, UEGW and

other meetings. Then we have reports from Y-ECCO, N-ECCO, and advertisements for grants, upcoming events and congresses. Some of our members have contributed greatly by describing both their scientific work and IBD working groups in different parts of Europe. 26,000 copies of each issue are distributed to health professionals with an IBD interest throughout Europe. For 2011, Y-ECCO has the intention to give reports on the best of recently published IBD papers, an excellent initiative. We are now into our fifth year and it's time for new ideas, so please come up with some suggestions on how to improve our ECCO News!



Per Lundblad (Mediahuset – ECCO News)

The Journal of Crohn's and Colitis (JCC)

In parallel with this, JCC was launched at the ECCO Congress in Innsbruck and has been growing. It is set to take off now: In December 2010 it appeared on Medline. Although it started a year after ECCO News, it is now a very strong part of ECCO. JCC is our scientific journal, allowing us to publish scientific work in IBD. Its impact factor just two years after publication rose from 0.812 in 2008 to 1.729 in 2009. It was indexed by the National Library of Medicine in Pub Med, a huge step forward, at the end of 2010. JCC is performing very well, doubling every year the number of submissions and decreasing sharply the rate of acceptance, now near 40%. JCC also publishes the abstracts of the ECCO Congresses and the full ECCO Guidelines. Publishing the Consensus in our own scientific journal is a great advantage, since there are no copyright problems when the guidelines are revisited and reviewed on a regular basis. Much of the text can be kept as it is and only new aspects or concepts added and some removed, of course. The Consensus papers add immensely to the value of JCC since they are read and cited most frequently.

The JCC is the brainchild of Miquel Gassull and he, together with Eduard Cabré and the editorial board have done a fantastic job in establishing a new scientific journal in a very competitive market.



Olle Lundblad (Mediahuset – ECCO News) and Miquel Gassull (Chief Editor of JCC)

Hopefully ECCO Members will send more of their work to JCC. That's the way to promote JCC as the world leading IBD Journal. Now that it is on PubMed, why send it across the Atlantic? I am told that the process from submitting to publication is among the fastest in the medical publishing world, another good reason to use our own scientific journal.

Tom Øresland

Treasurer's view:

A decade of growth and success



Being Treasurer of a society means that people have confidence in that person. So when the ECCO Governing Board asked me whether I would be interested in such a position, I immediately expressed my interest. Having served as Treasurer for other societies in earlier times of life, I knew that dealing with the finances of an international society would be a challenging task. At that time the budget of ECCO was still rather small and one of my first achievements was to organise the ECCO Congress in Innsbruck in 2007. At the ECCO Congress in 2006, when I started as Treasurer, we had not yet decided where to hold the meeting in 2007. Indeed, but for the success of Amsterdam 2006, we weren't even sure that there would be a 2007 Congress! This was my chance and I offered our excellent conference centre as an attractive opportunity.

The Innsbruck meeting was not only a great success because of its solid science, but also socially and economically. Just look at the numbers in the article on the congress: 500 delegates to Amsterdam, 800 to Innsbruck. It helped to secure our budget and to increase our revenues, as have all the following meetings. It became clear that besides the generosity of our corporate sponsors, successful annual meetings would stabilise and support our organisation in a major way.

An important decision was that we as ECCO Governing Board decided from the beginning that we would manage our money very conservatively. That meant no speculation and creating a contingency fund. So luckily, we not only did not lose any money in last years' financial crises, but we actually increased it. That's Austrian banking for you! Being ECCO Treasurer over the past five years had been a wonderful opportunity to contribute to this exciting movement in IBD. I really cannot express stronger words of support for this organisation and express my thanks to everyone for their "tremendous trust".

All the best to ECCO, this most admirable organisation.

Herbert Tilg

Working for ECCO

***Coming together is a BEGINNING,
Keeping together is PROGRESS,
Working together is SUCCESS.***

Henry Ford

The BEGINNING – coming together

My first day of work at ECCO was on March 1, 2007 – it was the day my relationship with ECCO began. I was driving with my team to the 2nd Congress of ECCO, which happened to be in Innsbruck that very year. Only a few days prior had I signed my employment contract with *vereint* – an association and congress management company servicing ECCO. When I first learned of ECCO, my initial thought was, “It’s a really catchy, hip name.”

During the four-hour drive, I was sitting in the backseat of the car flicking through materials, trying to get a grasp of ECCO and pondering what I should expect in Innsbruck and the future.

We parked the car and as we were approaching the entrance of the congress centre, equipped with our laptops, all of a sudden somebody shouted: *“Hey there, how are you doing? Good to see you.”* That’s Pia Munkholm from Denmark, the first ECCO person I met. We made our way through the crowds of people and finally reached the meeting room: *“Hello, you have arrived safely! Let’s get started with our Governing Board meeting.”* That’s Boris Vucelić

from Croatia, the second ECCO person I met. I entered the meeting room and instantly froze for a few seconds when I started to count the people in the room: *“...3, 4, 5, 6... How many of them are there?”*

The PROGRESS – keeping together

As time passed, the foundation of trust was laid. Everyone worked closely together on a daily basis, to ensure a professional performance. In May 2010, a major change occurred. The reorganisation of the administrative body was accomplished by establishing the ECCO Office in Vienna. The ECCO Office team has been enriched by three highly motivated ladies: Melanie, Stefanie and Barbara. They were immediately captured by ECCO’s enthusiasm and passionately joined forces to fulfil ECCO’s aspirations.

Now, each morning I read through my emails and pour myself some tea in a cup displaying the Beaufort scale; it was a present from Simon at the inauguration of the new ECCO Office in Vienna. *“Hold on to it, it might become a bit stormy,”* he said. His advice has been well received because sometimes the ECCO ship does sail through rough waters. However, all



ECCO Office team (Stefanie, Barbara, Nicole and Melanie) celebrating after ECCO meetings, UEGW Barcelona 2010

hard work and undertakings are worthwhile since, in the end, it is the patient's health that everyone within ECCO is striving to maintain.

Although ECCO Officers are constantly travelling around the globe spreading ECCO's message, they can always be reached via email, phone, text message, instant messenger or any other social media – you name it. *“Daan, hello? Can you hear me? Do you have a minute? I need to talk to you about the contract for our new ECCO IT infrastructure.” “Hang on a second, right now I am in my motorhome in the woods. I will need to climb up the mountain to hear you better since I hardly have any coverage up here.”* No matter whether the ECCO President is in an outpatient clinic or simply on vacation, he always makes time and lends an ear.

The SUCCESS – working together

Some people refer to their profession as just a job, but working for ECCO is definitely not “just a job”.

Working for ECCO is working together and, to me, this means friendship, teamwork, a sense of belonging, trust, devotion, a professional attitude, motivation, inspiration and, above all, adventure. A day with ECCO is hard to describe since not one single working day is the same as another.

Looking back I have to say it is an honour being part of the ECCO Family and contributing to ECCO's success story. In the past four years ECCO has tripled the number of delegates at

the ECCO Congress and has established a very competitive, high-level scientific programme. ECCO has achieved a track record of effective educational workshops to circulate ECCO Guidelines around the globe and has created a dense network of peers conveying the same principles – the “**ECCO Spirit**.”

Looking at the present and into the future, ECCO is going to set many more milestones on its journey, involving further ambitious and challenging tasks. The ECCO Office team is eager to contribute to the organisation’s mission in every possible way and embraces ECCO’s philosophy of working together, which has been, and still is, the foundation of ECCO’s achievements.

Nicole Eichinger



Visit us, the ECCO Office team, in Vienna!

ECCO and EFCCA:

Cooperation with the European patient's organisation

The European Federation of Crohn's & Ulcerative Colitis Associations, known as EFCCA, was founded in Freiburg in 1990 following discussions among a number of national IBD patient organisations, who had seen a need to meet and work together for the benefit of the then **estimated 0.75 million people across Europe diagnosed with IBD**. This was some ten years before the birth of ECCO.

EFCCA's 13 founding national member Crohn's and Colitis patient associations were afterwards – year by year – joined by new associations, many of whom were encouraged by EFCCA to develop, so that in year 2010 24 national groups are part of the "EFCCA family" and negotiations continue with other IBD patient groups.

While working on the statutes in those early years representatives were involved in an EFCCA patient perspective Quality of Life Project, the results of which were later presented at a Falk Foundation IBD patients seminar in Freiburg. A social security report was also produced about the commonalities and the differences of national social systems.

Information about **travelling with IBD** was also collected from each of the country associations so that TIBD booklets could be made available to the increasing numbers of people able to

travel throughout Europe regardless of their chronic condition. Later the IBD Travel info became available in factsheet format from the EFCCA website (www.efcca.org).

During those early years, apart from the resources provided by actively committed volunteers, money was in short supply.

The Falk Foundation which had assisted EFCCA even in its formative days, continued to provide facilities so that an annual General Assembly and accompanying programme in which two delegates from each member association participated, could be held in different cities of Europe.

These regular three-day annual events were vital in developing the concept of a credible European IBD patient community, working together for the well being of all people with IBD, whether as members or not. The EFCCA Medical Patrons soon spoke of more than one million Europeans with IBD!

In mid 1995 when first coming to EFCCA as a NACC UK delegate and immediately being elected as Treasurer, Rod Mitchell was told that the EFCCA Executive Committee meetings were held in a seminary near Antwerp. To this day he believes that the camaraderie and better understanding of each other's way of life in that often peaceful Belgian "Middleheim"



Rod Mitchell (EFCCA Chairman 1998 – 2008), speaker at the 3rd Congress of ECCO, Lyon, 2008

environment, helped them all to remove perceived barriers and to move forward constructively in developing EFCCA's role in support of people with IBD, through working at the European level and beyond.

EFCCA created policies for **building relationships** with other healthcare stakeholders and later formal partnerships with industry and other organisations. It was in 1996 that EFCCA was first represented at the United European Gastroenterology Week in Paris. Since then EFCCA has exhibited each year and occasionally taken part in connected IBD seminars so raising awareness both of EFCCA and IBD patients' needs and concerns.

Shortly after invitations were received from the **ECIBD Epidemiology Group** for two EFCCA patient representatives to join their Europe-wide

projects as observers, the cooperation quickly developed into opportunities for regular and constructive interaction in the half yearly project business meetings with discussions in between.

EFCCA Chairman Rod Mitchell (1998 – 2008) well remembers the accompanying ECIBD social evenings where everyone attending was "obliged" to sing for their supper! At the time EFCCA was considering words for an IBD song to the music of Aida, so this was the EFCCA duo's late evening contribution over a good many years and in which we were often accompanied by the multinational doctors and researchers in the very open, friendly and musically minded ECIBD Project Group (now merged with ECCO and known as EpiCom).

The new millennium saw the birth of the European Crohn's and Colitis Organisation – ECCO. As a result of relationships developed

with EFCCA Medical Advisers, other gastroenterologists and IBD health care professionals and stakeholders now part of ECCO, EFCCA were invited to take part in many of the early ECCO programmes and to participate in half yearly business meetings and the General Assembly.

EFCCA representatives were also invited to take part in the ECCO Congresses, in early Y-ECCO and N-ECCO events and importantly in the first ECCO Guideline discussions on Crohn's Disease and Ulcerative Colitis. As EFCCA Chairman, Rod Mitchell was indeed pleased to have been available for consultation and to provide a regular voice and input, all of which contributed to having a better understanding of ECCO's work and programmes.

We are pleased to learn that subject to the formal agreement of planned changes which will lead to the creation of an ECCO Strategic Council, **EFCCA will have a seat on the new ECCO "advisory" body with the opportunity once again to provide a formal patient voice.**

For more than ten years in addition to its Europe-wide and EU role and the development of further interaction with the 24 European member associations, EFCCA has had opportunities to develop working relationships with, among others, major sister IBD patient organisations around the world (Australia, Brazil, Canada and the USA) and to attend and exhibit at the Digestive Diseases Week – DDW in the USA.

More recently, EFCCA has been part of the Steering Group which launched the **first World IBD Day** in May 2009. This is to become a regular date on the global calendar given the ever increasing interest in IBD and the number of people of all ages being diagnosed with these debilitating often life-long diseases for

which currently we see no cause or cure.

We look forward to increasing our cooperation with ECCO and to the next ten years, though for the sake of the people with IBD – **now estimated at up to 2.5 million Europe-wide and perhaps five million world-wide**, we hope that enhanced collaboration together with other stakeholders might lead to further improvements in the quality of life of people with IBD through improved treatment and a better understanding of these often still difficult to manage chronic conditions.

Congratulations ECCO for achieving so much in your first ten years!

Rod Mitchell (EFCCA Chairman 1998 – 2008)
Marco Greco (EFCCA Chairman 2008 onwards)

In memoriam



Antoni Obrador at the XVI GETECCU Meeting in 2005 when taking over the presidency from Miquel Gassull

Antoni Obrador (1951 – 2006)

When we celebrate ten years of existence of ECCO, we should remember those who with his or her efforts, sometimes back stage, but avoiding personal promotion, those who greatly contributed to the early critical steps in establishing our society.

Antoni (Toni) Obrador, was one of the founders of ECCO, as Vice-President of the Spanish Group for the Study of Crohn's Disease and Ulcerative Colitis (GETECCU: A group already 21 years old). He attended the founding meeting at the Hotel Regina in Vienna. As Vice-President first and as President of GETECCU afterwards, he was the Spanish Representative at the ECCO Council of National Representatives until his death on November 28, 2006.

Antoni Obrador was a very close friend of mine for almost 30 years and for me it is still very difficult to write about him. Toni was a real human being. He had very firm ethical convictions while, at the same time, a very open mind. He had fantastic common sense and always managed to find the right door to open in any difficult situation, without ever renouncing his convictions. He was also always very respectful to everyone, regardless the status.

He developed intense activity in GETECCU. Toni, together with Joaquín Hinojosa, Fernando Gomollón and myself organised for many years the annual meetings of GETECCU, the quarterly Continuous Education Journal "IBD updated" (Eil al día), GETECCU Newsletter and the biannual "IBD Intensive Junior

Course" (running for more than 15 years), which is the precursor of the "ECCO Junior Gastroenterologist Course".

Antoni Obrador, was head of the department of Gastroenterology at the Hospital Son Dureta in Palma de Mallorca. He was an excellent, judicious physician and researcher. His main topic of research was epidemiology and he performed and published prominent works on the epidemiology of colon cancer in Mallorca, where he established the first proper registry in Spain. He became well known in the field and collaborated with other European working groups. He also established an IBD research group on his island. Dr. Obrador was a man of vast culture. He was an expert in Mallorquinian traditions and literature, appointed member of the Royal Academy of Medicine of the Balearic Islands and when he took over his seat in the academy, he delivered a lecture entitled "The medical diagnostics and remedies in the

traditional fairy-tales of Mallorca" delivered and written in the Balearic variant (Mallorquí) of the Catalan language. He was highly respected by all who knew him.

Those who had the privilege of being friends with Toni still miss him very much. His lively spirit and positive attitude facing the disease, even in the final days of his life, when I visited him in the hospital in Mallorca, and also the evening before his death when I spoke with him on the telephone, were moving. He never gave up and talked about future projects of GETECCU.

Antoni Obrador has left a profound impression on all of us because of his personality, integrity, wisdom and refined sense of humour. To honour Toni, GETECCU has created a Research Grant in epidemiology after his name.

Miquel Gassull

In memoriam



Marc Lémann

Marc Lémann (1956 – 2010)

Marc Lémann, was born on June 27, 1956 in Paris and died suddenly on August 26, 2010, while on a beach on Reunion Island.

Marc gained his baccalauréat at the age of 17 in Marseille and undertook his medical studies in Paris, in the university hospital of Pitié-Salpêtrière (1973-1979). He became an intern at the age of 24. He accomplished his military duty at Saint-Denis de La Reunion. He specialised in Hepatogastroenterology during his internship (1981-1985). After one year as an assistant at Antoine Bécclère hospital, he turned to research for two years (1986-1988) in the INSERM unit U290 headed by Professor J-F. Desjeux, at Saint-Lazare Hospital. He went back to Clinical Gastroenterology at Saint-Lazare Hospital as an assistant and then moved to Saint-Louis Hospital (1988-1991), where he became teaching practitioner (1992-1995), hospital practitioner (1995-2000) and ultimately University Professor – Hospital Practitioner (2000-2010). When Robert Modigliani retired in 2003, Marc Lémann was appointed as his successor as Head of the Hepatogastroenterology department.

This succinct outline belies the many dimensions, great breadth and substantive achievements of his career, touched always with a personal concern for his colleagues and patients that made him unique. Marc Lémann put his medical duties before all others. He combined intuition and high quality clinical reasoning. He treated patients as people, always sparing them time, so it is no surprise that many became attached to his care. Inflammatory

Bowel Disease was his main clinical focus and with it, his concern to raise the standards of care for these conditions. Marc developed clinical and translational research with his team participating in many trials of novel therapy. He was an expert investigator and creative thinker, driving many investigator-initiated trials and excelling at collaboration. The activity of translational research in IBD was supported by the recent development of the INSERM "Avenir" team, managed by his colleague, Matthieu Allez, at Saint-Louis Hospital. Gastrointestinal oncology became a new field of interest for his team, this activity being developed by his collaborator, Jean-Marc Gornet.

Marc Lémann and Emile Sarfati, Head of General Surgery at Saint Louis Hospital, created an exemplary and amicable medical and surgical cooperation, essential for the optimal management of IBD and GI cancers. In partnership with Emile Sarfati and Christophe Hennequin (radiotherapy), a committee of gastrointestinal oncology was created at Saint-Louis. Marc was the head of the group that brought together endocrinology, urology, nephrology, medical and surgical gastroenterology. He was involved in University education, teaching in his department and at his University (Denis Diderot). He participated in several inter-university programmes (IBD, surgical coloproctology) and in postgraduate teaching for gastroenterologists. His department was recognised as a training ground and centre of excellence, becoming a preferred choice for residents in Hepatogastroenterology.

His teaching and scientific lectures, always prepared with care, were crystal-clear. He was a warm and humorous speaker, conveying serious message with a friendly tone, smiling lips and twinkling eyes. He never missed a paradox or

the irony of a situation. Colleagues at all levels of expertise and seniority looked forward to his talks and attended them assiduously, knowing that they would find helpful ideas and original insights.

The fundamental research of Marc Lémann focused first on gastrointestinal motility and then IBD immunology. Marc's achievements will, however, be principally remembered for his clinical research on IBD through GETAID, created in 1983 by Robert Modigliani. He initiated or participated in many clinical trials evaluating immunosuppressant drugs and biological therapy, which have revolutionised the care of patients with IBD. He was a major player in international trials testing new molecular targets for the treatment of these diseases. He also recognised the need to define the cumulative burden of IBD and developed new indices, one of which has been named the Lémann Score and quantifies the extent of intestinal damage in Crohn's Disease.

However, his pre-eminent and favourite field was that of trials addressing therapeutic strategy. These trials were simple in concept in that they tested clinical practice, but they were robust in design and demonstrated a clear and practical vision of the disease. When two-arm randomised controlled trials were considered the state of the art, Marc designed and lead therapeutic strategy trials that became the principal engines for changes in practice.

Marc Lémann became Chairman of GETAID in 2002 and still assumed this charge in 2010. His chairmanship gave an extraordinary impetus to the group increasing and diversifying national and international studies that lead to high-impact publications. GETAID is now considered a major vehicle for investigator-initiated clinical or therapeutic research on IBD throughout the

world. It has become a force for progress and a model that international colleagues strive to emulate. Marc achieved this influence by his personality, seeking always to find the common ground for collaboration, motivating colleagues and resolving tension. His technique was disarming; when asked to explain his secret, Marc used to answer that it was the coupling between physicians and biostatisticians, internal democracy and mixing this all with friendship. He did not need to be more precise. He knew, quite simply, how to make different people work together in a friendly atmosphere; he knew how to bring out the best of everyone.

Marc was a member of European and International organisations dedicated to IBD. He contributed to the European Crohn's and Colitis Organisation (ECCO) from its inception and was an elected member of the International Organization for the Study of Inflammatory Bowel Diseases (IOIBD). Apart from being a major contributor to consensus documents on Ulcerative Colitis and Crohn's Disease, he was the spearhead for a Clinical Trials' Advisory Group in ECCO. Yet above all, it was his engaging personality that resolved disagreements and contributed so much to the "ECCO Spirit", encouraging young people and promoting collaboration. As a leading international expert on IBD and often invited to speak at conferences, his work resulted in 160 peer-reviewed publications, many published in major journals and others in the process of publication that will preserve his memory among his many friends and generations to follow.

That Marc was an exceptional practitioner, a brilliant teacher and speaker, a productive researcher and an outstanding organiser is not a formula for posthumous praise, but a faithful, first-hand reflection of the man with whom we

worked. His sharp intellect, open-mindedness, powerful capacity for work and remarkable efficiency were his conspicuous and widely-recognised qualities. The man was an active pessimist with a lucid irony. He cultivated and maintained friendship with the same rigorous warmth that he displayed in his work, making everyone feel like a special friend. It was his great store of medical and general knowledge that underpinned his penetrating and original thought. It is worth reading the many tributes that were recorded on the ECCO website and now summarised in a book (www.ecco-ibd.eu).

The sudden death of Marc, in the middle of his life, is a terrible bereavement for his father, his children Raphaëlle and Stanislas, his brothers and sisters Frederic, Isabelle and Florence, and all his family. It is the loss of a very dear friend to all who worked with him. His death leaves a sorrowful void. He is sadly missed at Saint-Louis Hospital, in the Faculty of Medicine, in French gastroenterology and in the entire world of IBD. He was to become the next President of the French National Society of Gastroenterology, just one of many reminders of his presence, which stir sadness and regret, but also admiration and affection.

May his children, family, friends, colleagues and everyone know how much we loved him. He has left an indelible mark.

Jean-Frédéric Colombel, Matthieu Allez,
Franck Carbonnel, Patricia Détré,
Yoram Bouhnik, Robert Modigliani
and the GETAID

The future of ECCO



President Daan Hommes demonstrating the ECCO App on the new iPad

Simon: *Daan, is it true that you suffer from megalomania? People are starting to refer to your future ECCO plans as "Megalodaan Plans."*

Daan: *Well, I don't know. I see myself as a pretty conservative person. What do you think?*

Simon: *I wouldn't call ideas like handing out free iPads to all ECCO Members, particularly conservative.*

Daan: *Ok, you have got a point. But I also see you as a highly modern innovator, especially the way you always wear Ferrari red trousers to ECCO Parties.*

Simon: *You like that? Jolly good! Well let's chat a bit about the future of ECCO, ok?*

Daan: *Let's first establish a Google Earth view on ECCO:*

Founding an organisation requires defining a mission, one that is not in the clouds but one that all of its members can relate to on a day to day basis. For NASA it is: "Taking people to the moon", for ECCO it is: "Improving the wellbeing of IBD patients". Very straightforward, very honest. Hence, all objectives and activities of an organisation must be directly linked to its mission. Progressing from an idea and a piece of paper in Vienna in 2001 to building an organisation that can truly contribute in the field of IBD implies a continuous flexible adaptation of the organisation. In general, there are different stages of development of any growing organisation. Although the speed by which organisations develop varies, the quality and success is largely dependent upon the principles that an organisation is willing to adhere to. These principles are not altered by the rapidly changing world around us, nor by politics nor any other transitory disruption. No, those principles are natural laws that will lead anyone into passionate execution of the tasks that are defined. In ECCO, we have formulated these principles among each other; we share these principles with our friends and colleagues within the IBD community and beyond. These principles motivate us to inspire others around us. These principles are often referred to as the "ECCO Spirit".

Simon: *Daan, this is pretty serious stuff, but I like it. I've always thought the "ECCO Spirit" also means working for the benefit of the organisation, rather than personal profile. Mind you, your profile's quite large enough already!*

Two of those principles that ECCO adheres to are 1) seeking constant innovation and 2) building trust and friendship. Progress and growth of an organisation means innovation; innovation means adaptation and change. Lack of continuous innovation means standing still. Standing still (sometimes referred to as consolidation) means stepping back, giving up and sliding back from the path to one's mission. Innovation is exciting, fun and very motivating! Innovation means involvement of everyone with a good idea. It is exactly this that has brought ECCO so much prosperity. We can enjoy the interest and commitment of young people, nurses, experts, scientists, paediatricians, new industry, surgeons and others from so many different regions of the world. Next, how do you build trust? Very simple: By avoiding (too much) politics, by ignoring personal agendas, by always considering win/win transactions, and by authentic behaviour. For example, take our National Representatives. Why would a country be interested in ECCO when its National IBD Group is doing well? First, ECCO tries to analyse the aims of National Groups, then we seek complementary deliverables. In other words, ECCO wants to strengthen National Groups on the one hand by offering products and services, but on the other hand ECCO wants to collaborate on a much larger scale, since ECCO believes in synergistic collaboration beyond borders. Further to this, a formidable exciting new step will be the ECCO Biobank Initiative which is currently being launched. The infrastructure that is used will serve as a platform for collaboration: An ECCO Framework Programme if you will.

Simon: *Daan, we might want to explain a bit more about the new structure that we put in place last year.*

Daan: *The one in your country house?*

Simon: *No, I don't want anyone to know that I am redoing my fireplace, bathroom and Jacuzzi.*

Daan: *You mean the fireplace around which the first SciCom sat in 2004 and redesigned the ECCO Logo?*

Simon: *Yes, uh no, I mean, let's explain why the new structure of ECCO has been installed for the future of ECCO.*

So what is this new structure about? Well, the new structure is about building infrastructure, working according to standards, securing the economic position and, most importantly, involving more kindred spirits, people that bring specific expertise and ideas to the table. The new structure is about allowing the "ECCO Spirit" to grow and develop our organisation, about preparing for future challenges.

The answers you need to know:

Question: Why is this the proper time to change the structure of ECCO, when everything seems to be going so well?

Answer: ECCO is growing considerably both in number of members and number of stakeholders. In addition we have started our own ECCO Office that will build a modern infrastructure around ECCO. This means that all of our operations need to be managed as effectively as possible, in separate committees, where the Governing Board needs to restrict itself to governance, strategy and innovation.

Question: So what does the new ECCO organogram look like?

Answer: As you can see in the figure, the structure of the Governing Board does not change. On a day-to-day basis we are in contact with the ECCO Office, as well as with our medical journal the JCC and the ECCO News. On the



left side, you can see that all operations are organised into our nine committees: SciCom, EduCom, GuiCom, EpiCom, ClinCom, Y-ECCO, N-ECCO, S-ECCO and P-ECCO. This Operational Board is a round table construction chaired by the Secretary and co-chaired by the Educational Officer as well as the Scientific Officer, thereby linking ECCO operations directly to the level of the Governing Board. Ideas are brought to the table, and proposals are brought directly to the Governing Board. On the right side, the former Council of National Representatives is replaced by the Strategic Council, allowing our Honorary Members to stay in the loop for advice and guidance. In addition, we will invite representatives from non-EU countries to our inner core. Some non-EU countries are eager to collaborate with us, and naturally ECCO embraces this. Also, we will invite other stakeholders into this council including patient organisations, regulatory agencies, and other IBD communities to share our common vision.

Question: What is meant by infrastructure and standards?

Answer: First, ECCO will present its new IT infrastructure in Dublin in February. The new ECCO data-warehouse will be a highly secure, fully equipped megastorage, high processing power database with an ECCO webportal, and applications like Client Management, Content Management, Abstract Handling application, eLearning modules and a lot more. Using state of the art applications and so called business intelligence (BI) tools for ECCO datasets (members, relations, activities etc) we will be able to install efficient decision-support tools allowing us to operate ECCO very effectively. In addition, we will be able to create a platform for our ECCO Community to interact, to share datasets, to use analytical and statistical tools, as well as free use of highly secure eCRFs for clinical studies. Again, ECCO wants to facilitate, not to own the data! The opportunities seem endless, and I am sure that a new generation of young ECCO experts will start

using the ECCO platform to its fullest potential. Second, we have started introducing ECCO Standard Operational Procedures to serve as a framework for all our activities. An example: Each of the nine operational committees is required to submit their annual plan in a highly formatted way along with budget and timelines.

Question: Is ECCO's ambition to be the global IBD organisation?

Answer: No, quite on the contrary! Europe including Israel is our playing field, but we are looking forward to working with the Americas, Africa, Russia, Asia and the Pacific because collaboration and sharing knowledge will greatly enhance the overall outcomes which serve to improve the wellbeing of IBD patients, which is our mission. We hope to form sister organisations on a global scale.

Question: The industry is mentioned often in the new structure, will ECCO not be influenced by all this interaction?

Answer: Not at all! This is a common misconception. The industry is essential for any medical society or organisation. We have an aversion to the simplistic view on how the industry is perceived. The industry is the key for developing new drugs, new devices, nutritional products, cellular therapies and much more. Where would we be, and more importantly our patients, without the industry? We are not, and never will be in a position to develop these innovations. However, we will always adhere to the principle of an unbiased choice with only the benefit of our patients in mind. Within our ECCO Family, the industry is very welcome to become a Corporate Member, but without voting rights in our General Assembly, again translating the principles of ECCO into practice. A full disclosure of interests of all members of the Governing Board and Committee Members can be found

on our website. Indeed, we should advise and assist the industry in their developmental programmes to maximise the end product for the benefit of improving care of our patients with IBD. There goes our mission again! It is also difficult to generalise the industry into one group and unsophisticated when critics choose to cast industry as an entity like a bucket of pitch. We invite not only traditional big pharma with already marketed drugs, but also the small start-up companies which will greatly benefit from our guidance and network. In February, we will have an interaction with existing and potential Corporate Members to offer a more differentiated package, tailored to individual firms.



President-Elect Simon Travis – sailing into ECCO's future

Daan: *Ok Simon, I think we have given a robust idea of what we intend for ECCO's future, don't you think so?*

Simon: *Yep, I think so. You might want to mention that we are always looking for new team players in ECCO, especially in the coming five years. And also that the dress code for the ECCO Interaction: Hearts and Minds for the coming years is "Dress to Impress"*

Daan: *Good Lord, does this mean you are going to wear your red trousers again?*

Simon: *Good Lord, no! Innovation, adaptation and change, remember? That's ECCO!*

Daan Hommes, Simon Travis

Memories



The famous trio, Lyon, 2008

Memories of Lyon

The European Crohn's and Colitis Organisation is unique in many aspects, but when it comes to balancing science with friendship there is no competition. The ECCO Congresses always excel in scientific content and undoubtedly have matured into the most successful and best attended "niche" meetings in IBD globally. Colleagues from all over the world have come to our recent meetings and they all agree that the icing on the cake of every ECCO Congress is the get-together party on Friday night. Infamous memories of splendid locations such as the converted monastery in Prague with DJ Walter and the aquarium in Hamburg still haunt my brain. One party, however, flashes back to me more intensively since this summer. The one in Lyon, an intense and heartwarming experience that ended abruptly in the middle of the action. The reason I have been thinking about Lyon in the previous months is the memory of a unique

personality, Marc Lémann, who represented everything ECCO stands for. There will be no more pictures of Marc at any of the parties. Intense, heartwarming memories remain of a man whose life ended too early and without any warning.

Gert van Assche

"Use the mousse"

This was a statement by Marc Lémann during one of the ECCO meetings while chairing together with me.

The speaker did not know how to point to the slides. "Please, use the mousse (mispronunciation of mouse)" was Marc's advice. This is how I will always remember Marc – with a big smile for his grandiose sense of humour.

Séverine Vermeire

Development of logos

2011



2010



2007



2005



2001



	6 th ECCO IBD Advanced Course, Lyon
	1 st Y-ECCO Workshop, Lyon
	2 nd N-ECCO Network Meeting, Lyon
	1 st Scientific Workshop, Vienna
	3 rd -7 th ECCO Educational Workshop: Portugal, Turkey, Poland, Greece, Lithuania
2008	ECCO IBD Forum (Budapest, Istanbul)
	Revision of ECCO Statutes
	First issue of JCC published
	ECCO Guidelines: Ulcerative Colitis (first guidelines published)
	Foundation of EpiCom (from ECIBD)
	Foundation of Y-ECCO
	Foundation of N-ECCO
	Introduction of ECCO Travel Awards
	2 nd Congress of ECCO, Innsbruck
	5 th ECCO IBD Advanced Course, Innsbruck
	1 st N-ECCO Network Meeting, Innsbruck
2007	1 st -2 nd ECCO Educational Workshop: Croatia, Austria
	ECCO News: First issue published at UEGW Berlin
	Publication of "Who is Who" in ECCO
	Introduction of ECCO Grants
	1 st Congress of ECCO, Amsterdam
2006	4 th ECCO IBD Advanced Course, Amsterdam
	ECCO Workshops on Biological Therapy (Prague, Stockholm, London, Barcelona)
	Revision of ECCO Statutes
	Introduction of ECCO Fellowships
2005	3 rd ECCO IBD Advanced Course, Poftu Quatu
	Foundation of SciCom and EduCom
2004	2 nd ECCO IBD Advanced Course, Dubrovnik
	First ECCO Guideline on Crohn's Disease plenary session (Prague)
2003	Introduction of ECCO Guidelines
	1 st ECCO IBD Advanced Course, Prague
	First ECCO Governing Board meeting, Palma de Mallorca
2002	First ECCO website
	Formation of the ECCO IBD Advanced Course (conceptual phase)
	Foundation of ECCO
2001	ECCO and UEGF: Associate Member of UEGF
	Draft of first ECCO Statutes

ECCO Milestones

2011	10 year ECCO Anniversary
	Publication of 10 year ECCO Anniversary Book
	ECCO Guidelines: Ulcerative Colitis update
	ECCO Guidelines: Reproduction on IBD
	6th Congress of ECCO, Dublin
	9th ECCO IBD Advanced Course, Dublin
	4th Y-ECCO Workshop, Dublin
	5th N-ECCO Network Meeting, Dublin
	2nd N-ECCO School, Dublin
	19th-23rd ECCO Educational Workshop: Finland, Croatia, Spain, Italy, Japan
2010	New ECCO Statutes approved at Extraordinary General Assembly, UEGW Barcelona 2010
	Introduction of new ECCO Structure
	Establishment of own ECCO Office, Vienna
	ECCO Guidelines: Pregnancy
	ECCO Guidelines: Reproduction on IBD
	ECCO Guidelines: Crohn's Disease update
	ECCO Guidelines (collaboration with paediatricians): International Consensus on Management of Pediatric Acute Severe Colitis (New Orleans)
	5th Congress of ECCO, Prague
	8th ECCO IBD Advanced Course, Prague
	3rd Y-ECCO Workshop, Prague
2009	4th N-ECCO Network Meeting, Prague
	1st N-ECCO School, Prague
	2nd Scientific Workshop, Prague
	13th-18th ECCO Educational Workshop: Brazil, Ukraine, Hungary, Latvia, Ireland, Bulgaria
	ECCO Guidelines: Opportunistic Infections
	JCG: Impact factor in Medicine doubled (1.729)
	4th Congress of ECCO, Hamburg
	7th ECCO IBD Advanced Course, Hamburg
	2nd Y-ECCO Workshop, Hamburg
	3rd N-ECCO Network Meeting, Hamburg
2009	8th-12th ECCO Educational Workshop: Israel, Romania, Norway, Russia, Serbia
	Introduction of individual membership
	JCG: First impact factor in Medicine (0.812)
	ECCO Guidelines: Crohn's Disease
	OMED-ECCO Guidelines: Small Bowel Endoscopy in IBD (Brussels)
2009	3rd Congress of ECCO, Lyon



Who is this statue pointing at?
Congress delegates at ECCO Congress



Auditorium, 2nd Congress of ECCO, Innsbruck, 2007



The ECCO gang in Innsbruck, 2007



Herbert Tilg, Geert D'Haens and Patricia Geens tasting Austrian mulled wine, Innsbruck, 2007



Miquel Gassull, Gerassimos Mantzaris, Herbert Tilg, Innsbruck, 2007



Wine tasting with Arthur Kaser, Innsbruck, 2007



The "Travis Smile", Simon Traivs (President-Elect), Innsbruck, 2007



Boris Vucelić (former EduCom Chair) and Pia Munkholm (EpiCom Chair), UEGW Berlin, 2006



Where is the answer to this question again?
Jean-Frédéric Colombel, Marc Lémann and Walter Reinisch, UEGW Berlin, 2006



Gerassimos Mantzaris, UEGW Paris, 2007



ECCO's advance with one question after the other, UEGW Paris, 2007



Daan Hommes (President) and Yehuda Chowes (SciCom Member), UEGW Paris, 2007



ECCO Baby Juliette (S  verine Vermeire's daughter), 4th Congress of ECCO, Hamburg, 2009



The ECCO Governing Board?
Michael Kamm's presentation at 4th Congress of ECCO, Hamburg, 2009



Eduard Stange (former GuiCom Chair), 3rd Congress of ECCO, Lyon, 2008



World Congress of Gastroenterology, London, 2009



ECCO Governing Board at 4th Congress of ECCO, Hamburg, 2009



ECCO Fellowships (Sala and Strisciuglio) with Matthieu Allez (SciCom Chair),
5th Congress of ECCO, Prague, 2010



What is Jean-Fred looking at?
Best Posters Award Ceremony at 5th Congress of ECCO, Prague, 2010



The "Travis Look", UEGW Barcelona, 2010



ECCO Office team, UEGW Barcelona, 2010



Mmmh, interesting what Séverine is telling us today?
Jean-Frédéric Colombel (Past-President), Séverine Vermeire (Secretary), Walter Reinisch
(former Secretary), 4th Congress of ECCO, Hamburg, 2009



President Jean-Frédéric Colombel and Past-President Miquel Gassull, 3rd Congress of ECCO, Lyon, 2008



Miquel Gassull, Daan Hommes, Séverine Vermeire, Boris Vucelić, Tom Øresland, 3rd Congress of ECCO, Lyon, 2008



Live-endoscopy Session, 3rd Congress of ECCO, Lyon, 2008



ECCO with S-ECCO, 4th Congress of ECCO, Hamburg, 2009



What does Renzo Caprilli (Past-President) try to explain?
3rd Congress of ECCO, Lyon, 2008



ECCO Grants with Simon Travis, 3rd Congress of ECCO, Lyon, 2008

socialising



Master DJ Walter and his apprentice DJ Jean-Fred in action



Is Daan the only man at this hen party?
5th Congress of ECCO, Prague, 2010



Dancing at the ECCO Interaction



On the dance floor
3rd Congress of ECCO, Lyon, 2008



Empty plenary hall: Everybody has left for the ECCO Interaction, Hamburg, 2009



Handing over Presidency, Prague, 2010



At the aquarium in Hamburg: Ready for a snorkelling tour!
Hamburg, 2009



Everybody on the dance floor, 2010

socialising



The French connection



Full steam ahead
5th Congress of ECCO, Prague, 2010



The next dance is on me!
Matthieu Allez and Séverine Vermeire, 3rd Congress of ECCO, Lyon, 2008



At least someone is looking into the camera
UEGW Vienna, 2009

socialising



ECCO dining at Miquel Sans' home, Barcelona, 2010



"Handyman" Simon Travis (President-Elect), Barcelona, 2010



Herbert Tilg (Treasurer) keeping an eye on the treasure, Barcelona, 2010



Do you want some coffee?
Andreas Sturm (SciCom Chair), Barcelona, 2010

socialising



SciCom session in the hot tub
UEGW Barcelona, 2010



Who has the biggest smile?
Andreas Sturm (SciCom Chair) and Axel Dignass (GuiCom Chair), Barcelona, 2010



Who's that?
Barcelona, 2010



Let's talk it over with some champagne! Daan Hommes (President) and Simon Travis (President-Elect) at the house of Miquel Sans, Barcelona, 2010



Was it really one Reindeer and four times Santa Claus?
Rome, 2005



Live-performance, 1st Congress of ECCO, Amsterdam, 2006



Boris Vucelić working on the ECCO Statutes



EpiCom meeting, Gastron London, 2009



Faculty of the 13th ECCO Educational Workshop, São Paulo, 2010



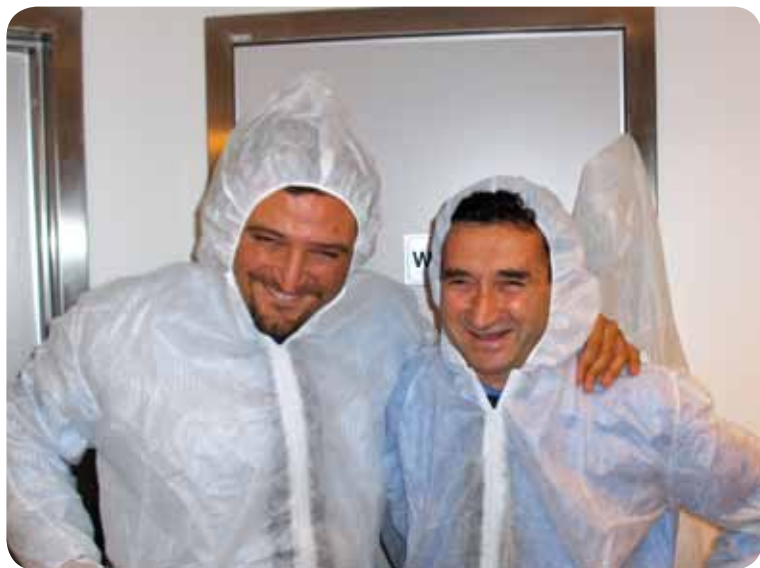
Faculty of the 4th ECCO Educational Workshop, Athens, 2008



Presidents of ECCO



Geert D'Haens getting a proper tie knot, 2nd ECCO Congress, Innsbruck, 2007



Silvio Danese and Michael Kamm on ECCO expedition, IBD meeting, Sweden, 2006



Simon Travis looking forward to his ECCO Presidency?



Founding Father Renzo Caprilli



Our Presidents

List of abbreviations

ACCU	Confederación de Asociaciones de enfermos de Crohn y Colitis Ulcerosa de España
AEG	Spanish Association of Gastroenterology
BI	Business intelligence
BIRD	Belgian IBD Research Group
BSG	British Society of Gastroenterology
CD	Crohn's Disease
ClinCom	Clinical Trials' Advisory Group/Committee
DDW	Digestive Disease Week
EASL	European Association for the Study of the Liver
ECCO News	ECCO Newsletter
ECCO	European Crohn's and Colitis Organisation
ECIBD	European Community Inflammatory Bowel Diseases
EduCom	Education Committee
EFCCA	European Federation of Crohn's and Colitis Associations
EMA	European Medicines Agency
EMA	European Medicines Evaluation Agency
EOMIFNE	Hellenic IBD Study Group
EPACT	European Panel on the Appropriateness of Crohn's Disease Treatment
EpiCom	Epidemiology Committee
EU	European Union
EUR	Euro
GB	Governing Board
GEDII	Portuguese IBD Study Group (Grupo de Estudos da Doença Inflamatória Intestinal)
GETAID	French IBD Study Group (Le groupe d'Etude Thérapeutique des Affections Inflammatoires du Tube Digestif)
GETECCU	Spanish IBD Study Group (Grupo Español de Trabajo en Enfermedad de Crohn y Colitis Ulcerosa)
GI	Gastro-Intestinal
GuiCom	Guidelines Committee
Gut	An International Journal of Gastroenterology and Hepatology
H1N1	Influenza A (H1N1)
IBD	Inflammatory Bowel Disease

IBDIS	Inflammatory Bowel Disease Information System
IBDSG	Russian IBD Study Group
IG-IBD	Italian Group for Inflammatory Bowel Diseases (Gruppo Italiano per lo Studio delle Malattie Infiammatorie Croniche Intestinali)
INSERM	Institut national de la santé et de la recherche médicale
IOIBD	International Organization for the Study of Inflammatory Bowel Disease
JCC	Journal of Crohn's and Colitis
METEOR	Methotrexate for Refractory Ulcerative Colitis
NACC	National Association for Colitis and Crohn's Disease (UK)
NASA	National Aeronautics and Space Administration
National Reps	National Representatives
N-ECCO	Nurses ECCO
NICE	National Institute for Clinical Excellence (UK)
OB	Operational Board
ORIGIN	Observing Relatives, Immunity, Genetics and the microbiome before the onset of Crohn's disease
PAC	Public Affairs Committee (UEGF)
P-ECCO	ECCO Paediatricians'
RCCC	Romanian IBD Study Group (Romanian Crohn's and Colitis Club)
SC	Strategic Council
SciCom	Scientific Committee
S-ECCO	ECCO Surgeons'
SRED	Romanian Society of Digestive Endoscopy
TIBD	Travelling with IBD
UC	Ulcerative Colitis
UEGF	United European Gastroenterology Federation
UEGW	United European Gastroenterology Week
UGA	Ukrainian Gastroenterological Association
UK	United Kingdom
US	United States
Y-ECCO	Young ECCO

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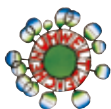
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