

A continued story of success:
Feeding science, digesting knowledge



European
Crohn's and Colitis
Organisation

20 year ECCO Anniversary Book



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Foreword



ECCO became a global organisation over the past 20 years. Every IBD specialist wants to speak at our congress, every gastroenterologist wants to attend our congress, and everyone (IBD specialist or not!) would like to attend the ECCO party. Here are a few numbers: almost 10,000 people attended our last physical congress, we have now 11 committees, and 1,000 people danced during the last Hearts and Minds event! We all know that losing the ECCO Spirit is the main risk when growing up so quickly. Creativity and friendship are probably the two main features of ECCO since its birth. The unique atmosphere of the congress is also something that everyone looks forward to when saving the congress date in their agenda. ECCO keeps evolving. The names of the speakers and chairs during the ECCO Congress and the committee members have changed a lot over the past years, with numerous new faces. Gender balance and

cross-generational representation of the IBD Community are hallmarks of ECCO. When thinking about the future of our organisation, we should not forget the founders or past GB and committee members, as they have all made ECCO a very successful organisation. We are also grateful to the ECCO Office, which takes care of all ECCO issues and any challenges throughout the year. An anniversary, especially the 20th one, is always a fantastic opportunity to make a wish for the future. We wish the best to all ECCO Friends and for a physical congress in 2022. The COVID-19 pandemic will not harm the ECCO Spirit and in the end, we are convinced that it could even reinforce it.

On behalf of the ECCO Governing Board

Laurent Peyrin-Biroulet,
ECCO President

Future of ECCO

Vision of development



GB online meeting

Janneke: Our live 2020 meeting, with again so many participants, meetings of our different committees, networking, and of course party, was fantastic! At that time nobody could have guessed that only a few weeks later these interactions would become impossible for so long. But we'll be back in 2022. Britta, what can we expect from future ECCO Meetings and can we dress up for the Hearts and Minds?

Britta: We will definitely dress up again, and the stars are aligned in our favour to do so for the Hearts and Minds in 2022! It is important that we meet again in person for several reasons. The central concern is that a new disease might spread in the IBD Community, which is definitely anti-TNF refractory and not curable by surgery- 'Zoomitis'. Networking takes place at the party, during breakfast, and in coffee breaks. This is particularly important for our Y-ECCO Members.

Janneke: I agree completely, to meet opinion leaders in person and to bring your own results

and to discuss them with others is pivotal not only for young researchers but for senior researchers as well! I miss these interactions. Turning on your computer to meet friends and colleagues is boring. Discussing in person provides a different dynamic, especially during our committee meetings, where so many good ideas are born. In-person exchange and friendships play a key role in the ECCO Network, and these are even maintained at a personal level. In addition, I feel that we must work on establishing virtual mentoring and exchange networks so that the current Y-ECCO Generation can be integrated into our network and their thoughts and ideas can be brought into the work of ECCO. There was a certain time for each of us when we started to build up our individual networks. Personal conversations or introductions from other ECCO Members played an important role. This is currently not happening and we must ensure that even in these times, these interactions and network building remain possible. In view of the current

‘virtual’ development, it also seems almost conservative to stick only to in-person exchanges. We will have to push this development together with Y-ECCO, the generation that was already more at home in the virtual world before the pandemic!

Britta: Absolutely, we need ECCO Dinners and the congress to allow our continuously growing ECCO Community to interact. Our expanding number of committees nicely illustrates how diverse ECCO is. This diversity is the key when managing a ‘diverse’ disease such as IBD. If one committee develops an idea and requires the expertise of a different field, you can just reach out to the dedicated committee. The committees clearly originated out of a need. For example, not too long ago, clinical remission and perhaps an endoscopic endpoint were sufficient in a clinical trial. Today, endoscopic and histologic endpoints have become standard. Ultrasound was once a technique performed in some ‘strange’ countries only. Our ultrasound workshops at ECCO Congresses have become increasingly popular and ultrasound is now practiced around the world.

Janneke: Yes, in the last decade we made amazing progress in improving IBD outcomes. With ECCO, we were able to reach for higher goals in the management of IBD. I feel that as an organisation we were pivotal, bringing together science, sponsoring innovative research (for instance with the pioneer grants), disseminating knowledge at our annual congresses, and of course raising the profile of JCC, which became so important in the world of gastroenterology journals.



GB Meeting

Britta: I am also thinking about the Educational Workshops, where personal discussion and exchange are at the heart of the agenda. Having said this, we should still consider what has changed since the COVID-19 pandemic started. The possibilities we have today (in contrast to 2019) for virtual meetings is fascinating and we should not ignore this. Instead, we should take advantage of this and implement the virtual world into ECCO. There will be meetings, workshops, and discussions that can certainly be organised virtually, and this will be reflected in our ecologic footprint. These virtual formats can improve networking in currently unforeseen ways and also facilitate the dissemination of IBD knowledge.

Janneke: Education has always been a focus of ECCO and was already partly virtual with the amazing facilities on the e-Learning platform, which really matured over the last decade. There are so many interesting cases available where one can learn about integrating guidelines in managing patients with IBD.

Britta: The e-Learning platform, which was built up over many years, appears to have



GB Meeting

been developed with a great deal of foresight even from today's perspective. This platform will undoubtedly be further expanded in the coming years. Virtual technologies will facilitate easier access to IBD education. One of my personal favourites are the podcasts. I started listening to podcasts during the pandemic more frequently and became a fan (yes, I admit that it took me a long time to realise this). The ECCO Educational Audio Podcasts are great, and I can also recommend the JCC podcasts. Tim Raine is doing a great job!

Janneke: How do you see the future of science in ECCO?

Britta: I would rephrase the question to how we want to approach science. Science is about visions, and, to some extent, about crazy ideas. The best projects are the results of lively discussions that mostly benefit from a healthy mix of people. ECCO has a network that includes people with visions, people with crazy ideas, and people who love to discuss. And we should never underestimate the younger generation and involve them early on. We will need to include even more basic scientists,

such as those with knowledge in upcoming technologies. These include single-cell techniques and artificial intelligence, among many others. As these technologies will be part of future clinical care, we need to anticipate and be a part of these developments. One part of this is the availability of structured clinical data for patients and potential biosamples. This has been made possible through the UR-CARE platform. The

development of the platform has been a bumpy ride, but the road is slowly smoothing out and I anticipate moving forward rapidly. Despite the pandemic, the number of centres and patients included has been increasing continuously. These structured patient data allow for both the search and evaluation of defined patient groups in your own centre, country, or even internationally. This means that this gap can be elegantly closed with UR-CARE for all centres that previously had no database. Furthermore, retrospective studies [e.g. the collection of real-world data at the centre, national, and international levels] can be performed with ease. Thus, UR-CARE not only has the potential to become the largest IBD platform, but also offers possibilities to use this platform at various levels. This example illustrates that there is a lot of room for the implementation of ideas and further development.

Janneke: Yes, UR-CARE will play an important role in the future of IBD. Looking beyond that, what will happen in the next 10 years?

Britta: Our hair will turn even greyer...

Janneke: Not mine, I have my tricks...

Britta: I can also colour my hair on Zoom! Jokes aside, the **virtual world** will continue to develop in ways we could not imagine. The developments of the last year provide ample evidence for this. It is up to us to take advantage of this opportunity within ECCO and begin developing our future formats. Y-ECCO, the generation that grew up with virtual technologies, will play a major role in this development and will be a key driver for this journey. ECCO has developed into the **largest IBD organisation** over the past years and will continue to grow. The networks are already dispersed to all parts of the world. With the further development of virtual formats, these networks will also grow outside of Europe and bring the ECCO Community even closer together. Our colleagues, friends, honorary members, volunteers for the ECCO Committees, and of course the ECCO Secretary, will make this development possible. In addition to the collective interest in IBD, friendships should stay in the heart of our organisation, as such friendships make unexpected connections in our networks possible.

Janneke: And I would like to add that patients with IBD are at the core of our organisation. These patients teach us what is important and also help us set our future goals in research and in patient care. We learned very quickly this last year that e-health will be further developed in the management of IBD patients and is an opportunity to investigate IBD behaviour in more detail.

Britta: All of us aim to provide the best possible care for our patients. Current developments



GB Meeting

will allow for an individual approach within this decade. Will IBD be solved in a decade, not sure. Until now, the field has been focused on disease-driving pathways. Perhaps we should instead consider which pathways maintain homeostasis and thus prevent disease. If it is possible to strengthen these pathways, we could consider this as “rethinking health” or “**rethinking IBD**”.

We both feel that ECCO has grown from its strong **interdisciplinarity**. There is interdisciplinarity and friendship between physicians from different fields, scientists, IBD Nurses, patients, and many others. This network within ECCO is the foundation upon which we build. The voice of all groups will contribute to further strengthening and developing ECCO into the next decade.

We look forward to the next decade, to introducing many new people to ECCO, and to new ideas, developments, surprises, and virtual technologies. But most of all, we look forward to the next ECCO Congress and party in person!

Britta Siegmund & Janneke van der Woude

ECCO@20

‘Fare forward, travellers...fare forward, voyagers!’

TS Eliot is back in vogue, not thanks to Brexit, but to Ursula von der Leyen. ECCO has always looked forward, not to the past, and it has been an exciting journey, no less the second decade than the first.

I assumed the Presidency of ECCO from Daan Hommes in 2012 as ECCO came of age. Daan oversaw a major reorganisation with the establishment of ECCO's now familiar structure of governance (www.ecco-ibd.eu/about-ecco). Less familiar was the divergence between expenditure and income. That was reversed through increasingly successful Congresses, with numbers of delegates rising from 3,509 (Dublin 2011) to 5175 (Copenhagen 2014) from 78 countries, sponsorship opportunities for satellite symposia, and increasing numbers of members. Financial security meant that ECCO could invest in all the activities that really mattered, since ECCO has always been more than just a Congress.

Between 2012 and 2014 ECCO established its own offices in Ungargasse (that was a fun time, looking to invest contingency funds in real estate); new publishers (Oxford University Press, with a profit-share in contrast to a royalty agreement – higher risk, but greater share in success – thanks to the authors and Larry Egan as Editor-in-Chief); e-CCO Learning and e-Guide (thanks to Janneke van der Woude and Marcus Harbord); bringing ECCO News in-house; Toolkits (Yehuda Chowers); CONFER cases; Digital Oral Posters (to increase the number of presentations at the Congress); opening up the ECCO IBD Intensive Course for Trainees

to applications from non-member countries; lunchtime satellites; the Educational Course for Industry; Global Forum (to help manage ECCO's international profile); Art-ImID (a collection of paintings, sculpture, and artwork conjuring up perspectives on IBD, psoriasis, or rheumatoid arthritis); and much more. Some initiatives did not materialise or took a different form, such as a joint application with UEG to the European Parliament for a written declaration on IBD; migration of the EpiCom database; joint initiatives with EFCCA; pizzas at the Copenhagen Congress; and the initial biosimilar position statement. How long ago that seems – but look to the future, not to the past.

ECCO has always been about people, placing the improvement of care for patients with Ulcerative Colitis or Crohn's Disease at the centre of its mission statement. And it is people that have made ECCO, volunteering their time through accredited positions on the Governing Board, chairing committees or memberships, speaking in the educational workshops, and collecting ideas from everyone. These ideas are corralled, co-ordinated and sometimes challenged by the ECCO Office, who deserve special credit. It is a special organisation, with both the vigour of youth and humour to avoid taking itself too seriously (consider the ECCO films), which has created the world's largest and most interactive organisation for specialists in IBD. Supporting each other to support patients. That is the spirit of ECCO.

Simon Travis

ECCO President 2012-2014



ECCO'14 Copenhagen

And the spirit of ECCO continued....

I took over the helm of the ship from Mr Simon – James Bond – 007 in 2014. Having started as a pupil in ECCO's very first student's course in Prague and moving up to ECCO's first Scientific Committee followed by 5 years as Secretary and President-Elect, I knew I was about to lead a very well structured and well-oiled organisation with financial security. With an amazing number of no less than 5,000 attendees at the congress in Copenhagen in 2014, I was determined to not only continue the successes achieved by the former presidents, but I was also determined to seek constant innovation and change, starting with a change in gender! Female representation on the various ECCO Committees and on the Governing Board was approximately 20 % in 2014 (an exception being N-ECCO, where the opposite was true) and we made it an endeavour to recruit talented young women to the Committees. I am

proud to see that female representation in ECCO today is remarkable, with women making 50 % of its Governing Board! This increased diversity within the ECCO Committees, also from our non-European colleagues, certainly contributed to improved creativity and innovation.

My first evening as 'Madame President' will be remembered as an evening where the traditional lovely dinner at ECCO's Heart and Minds was turned into phoning 136 pizzerias in the capital of Denmark to deliver all the pizzas they could bake! This was not really an example of Masterchef, but we were determined to provide a better menu in 2015 (which I believe we did, but I will let others decide)!

In 2014, Larry Egan also became the new Editor of the Journal of Crohn's and Colitis, after



ECCO'16 Amsterdam

Miquel Gassull had put JCC on Pubmed. Under Larry's guidance, JCC began a steep ascent and has become one of the leading journals worldwide, with an astonishing impact factor of 9.071. Again, how visionary were the founding fathers of JCC.

What followed were 2 years of frequent travelling between Brussels and the ECCO headquarters in Vienna, where I would always be welcomed by Nicole and her growing team of enthusiastic people at the ECCO Office. I have lovely memories of those days and the professional support provided by the office cannot be stressed and repeated enough. They are the real beating heart of the ECCO.

We gave birth to two new committees, D-ECCO and H-ECCO, and looking back 7 years later, they have grown up fantastically and are now an

indispensable part of the multidisciplinary IBD family. We also had some challenges ahead of us; the growing number of congress delegates made it difficult to select congress centres that could accommodate ECCO's unique 'one-program one-room' concept. By 2015, we had a record number of 5518 delegates from 80 countries around the world; future congresses would show that we had still not reached a plateau. While the expansion of ECCO activities has made the congress programme very dense with little flexibility, I prefer to see the ECCO Congress as a very intense week and an event nobody would want to miss!

Severine Vermeire

ECCO President 2014-2016

How can we get the best from our lives? When we live passionately.

When we live passionately, love, friendship, sports..., but also work, science and education. In ECCO I have found colleagues who have become very good friends over time, who share a passion for excellence in providing care to persons suffering from IBD, and who understand that we should work together in international initiatives across Europe. Thanks to this passion and a high degree of generosity, we have found in ECCO the means to interact and collaborate, to produce guidelines to improve patient care, to research projects to broaden our knowledge of these diseases, and to provide education at all levels.

The ability to recognise our limitations in knowledge and the willingness to help our friends and colleagues from other fields is in the DNA of the multidisciplinary units, which is the essential structure to provide optimal patient care in IBD. And this DNA at an international

level is what has led ECCO to its structural organisation and functioning. Although most ECCO Members are gastroenterologists, it is the contribution of nurses, surgeons, pathologists, paediatricians, dietitians, radiologists, and other specialities that makes ECCO the leading scientific organisation in IBD.

I assumed the ECCO Presidency from Séverine Vermeire in 2016. The challenge of continuing this successful project was great, but I received invaluable help from each and every one of the members of the Governing Board. It was a privilege to interact with all the committees and to improve and develop projects that would serve the IBD Community. This is the essence of ECCO. Live it with passion!

Julián Panés

ECCO President 2016-2018



ECCO'15 Barcelona



Improving the everyday IBD patient journey. Every day.



ECCO National Representatives Meeting & cooperation with EFCCA

The European Crohn's and Colitis Organisation (ECCO) continues to champion the involvement of IBD patients and the public in all aspects of its mission. ECCO fully supports the contribution of IBD patients to international guidelines and in educational meetings. Furthermore, ECCO encourages their role in research, from contributing to setting research priorities, designing research programmes, to participation in research and its dissemination.

The inaugural National Representatives Meeting was organised by ECCO in Vienna in December 2014. ECCO's objectives were to gain a fuller understanding of patients' perspectives, to identify and map joint collaborative initiatives, and importantly, to get to know each other. The first meeting hosted 60 participants from 25 European countries and included ECCO National Representatives, N-ECCO National Representatives, Patient Association Representatives, and representatives from the **European Federation of Crohn's & Ulcerative Colitis Association (EFCCA)**. EFCCA is an organisation founded in Frieberg in 1990 that now represents 45 national IBD patient associations. EFCCA and ECCO have had an important and fruitful relationship since the

early days of ECCO. The success and positive feedback from this first meeting led to a further National Representatives Meeting in Vienna in December 2016 with 80 participants from over 30 European countries. In Barcelona in October 2019 ECCO held its first Council of National Representatives meeting.



National Representatives Meeting 2014



National Representatives Meeting 2014



National Representatives Meeting 2014

Examples of achievements from these collaborative efforts include the translation of the ECCO-EFCCA Patient Guidelines, which were launched at the 12th Congress of ECCO in Barcelona. Patient and clinician representatives from each country were involved in translating the main ECCO Guidelines from medical to lay language and also into several different languages. The goal of this initiative was to offer patients and physicians an easily accessible common background of knowledge to facilitate dialogue, understanding, and shared involvement in decision making.

Another example of an exciting initiative that demonstrates collaboration between ECCO, National Representatives, and EFCCA was the ECCO Position Statement on Quality-of-Care Standards in Inflammatory Bowel Diseases, published in the *Journal of Crohn's and Colitis* in February 2020. Clinician and patient representatives constructed a list of criteria summarising standards of care in IBD that should be available to IBD patients. The criteria included

aspects pertaining to the structure of the IBD service, such as key members of the IBD multi-disciplinary team, facilities available within the IBD unit, and coordination of the IBD service. Other criteria included aspects of the processes within an IBD service, such as clinical pathways to ensure timely diagnosis of IBD and optimal monitoring of IBD. Finally, criteria to measure outcomes of the IBD service were considered, such that the performance of an IBD service can be measured in an ongoing manner and improved as required. The overall aim of this initiative was to raise the standard of IBD care by supporting negotiations to improve institutional

standards and to provide insights into future directions for the field of IBD in Europe.



National Representatives Meeting 2014

Improving education across the board, particularly IBD Nurse education, has been a focus of National Representatives in close collaboration with Patient Associations. The recognition that not all IBD patients across Europe have access to IBD Nurses has motivated us to address this issue. ECCO provides teaching material



National Representatives Meeting 2016

and facilitates an educational framework for IBD Nurses. Issues with language barriers to nurse education were also addressed. The IBD Nurse Education Programme organised by the Nurses of ECCO and the Education Committees has been a highly successful initiative. The goal of this initiative is to increase the knowledge and competence of the nurse participants and to empower IBD Nurses throughout Europe. The programme consists of the following three core pillars: face-to-face meetings; distance learning using literature and e-Learning materials; and a visit to an established IBD nursing centre.

The ongoing importance of integrating patient perspectives and close collaboration with Patient Associations and National Representatives cannot be overstated. ECCO remains

committed to these activities and will continue to maintain these initiatives at the heart of its activities.

Ailsa Hart & Fernando Magro



National Representatives Meeting 2016

New initiative by ECCO

Talking Global IBD

This new initiative was held for the first time at the ECCO 2020 Congress in Vienna. Societies from all over the world were invited to meet

and exchange in a networking atmosphere. All attending participants were very happy to meet and discuss the latest news of IBD.

Among the attendees were the

EDGE	Egyptian Developers of Gastroenterology and Endoscopy
EMA	Emirates Medical Association
EFCCA	European Federation of Crohn's & Ulcerative Colitis Associations
ESIBD	Egyptian Society of Inflammatory Bowel Disease
FUNDECCU	Fundación Argentina de Ayuda para les Personas con Enfermedad de Crohn y Colitis Ulcerosa
GECCOL	Grupo De Estudio de Crohn y Colitis Colombiano
GEDIIB	Brazilian Study of IBD
IBD Africa	Inflammatory Bowel Disease Africa
JSIBD	Japanese Society of Inflammatory Bowel Disease
KSSID	Kazakh Scientific Society for the Study of Intestinal Disease
TSIBD	Taiwan Society of Inflammatory Bowel Disease





Furthermore, ECCO started a new initiative called ***Affiliate Society Member of ECCO***, giving an opportunity to societies from non-ECCO Member Countries to become an ECCO Affiliate Society Member. Among the opportunities related to this are Hosting of an ECCO Educational Workshop, Society Profile Poster at the ECCO Congress, and a Society profile in ECCO News. Global Friends of ECCO Affiliate Society Member can also benefit from the opportunity to stand as a committee member for ECCO, reserved seats at the IBD Intensive Course for Trainees, and research cooperation via UR-CARE.

Silvio Danese



ClinCom

Ever since its founding in 2001, the declared objectives of ECCO were the promotion of international research and education to foster uniformly high standards of IBD management. The committee initially consisted of experts in clinical research and was initially focused on formulating research questions, guiding development of critical research protocols, and guiding conduct of clinical trials for academic and industry partners. As per the updated statutes in 2010, ClinCom has 5 elected members representing diversity and the ClinCom Chair represents the committee in the Operational Board meetings.

Since 2012, the committee has developed educational activities for clinicians with interest in and varying levels of experience in clinical research. The basic and advanced ClinCom Workshops cover all aspects of clinical research, from study designs, methodology, regulatory frameworks, and delivery and dissemination. The workshops organised by ClinCom soon became one of the highlights of ECCO Congresses,

with increasing demand from the attendees and encouraging feedback on the content. Researchers who have attended the ClinCom Workshops were stimulated by this exposure and were bitten by the 'bug of research' and have gone on to become research leaders in their own countries.

It was soon recognised that learning together with industry partners to advance research was beneficial. This led to developing the basic and advanced educational courses for industry. This was accomplished by inviting key researchers and representatives from regulatory bodies to deliver educational courses to meet the needs of industry partners. These courses presented the challenges faced by front-line IBD clinicians to the attention of our industry partners. This also provided an opportunity to understand the needs for future research and highlighted the urgent areas of research from a clinical practice perspective. These meetings also allowed regulatory bodies (such as the EMA) to enable reciprocal exchange of ideas between industry, researchers, and regulatory bodies.



ECCO'14 Copenhagen: 2nd Basic Course Industry

Following ECCO's desire to embrace the IBD national study groups of European and other member countries without dedicated study groups, in 2016 ClinCom set up the annual IBD National Study Group meetings to foster collaborations in clinical research and to promote an environment where clinical research was not limited by national boundaries. This was fundamental if we are to be successful in translating



ECCO'17 Barcelona: School for Clinical Trialists

the results from 'today's clinical research to tomorrow's clinic' by ECCO Members. Perhaps this has been the most successful and impactful venture of ClinCom, as this brought clinical research to the forefront of ECCO Membership and provided a platform for all ECCO Members from various national groups to actively participate in the core mission of ClinCom, which is to improve the quality of clinical research. This led directly to the implementation of several investigator-initiated studies (IIS). Over the last decade, ClinCom has assisted in the development of several high-quality IISs that have impacted IBD clinical practice. The open transparent call, provision of expert critical appraisal on projects, and facilitation of networking opportunities to improve recruitment have helped clinical researchers from all countries bring their research ideas to fruition. The investigators are given a platform to pitch their proposals at the well-attended IBD National Study Group Meeting at the ECCO Congresses and to showcase the outputs from their projects. Some recent outputs from this

process include the high-impact publications on conjugal twins led by Joanna Torres, the CONCEIVE study led by Marc Ferrante, and the ustekinumab dose-escalation study co-ordinated by Uri Kopylov. Organizing the annual calls and proposal reviews is a key role of ClinCom, and the committee always looks forward to receiving and reviewing these proposals. ClinCom also evaluates the best IIS abstracts at the ECCO Congress each year and presents awards to the two best IISs. Some of the studies that received this award led to high-impact publications, such as the recent CD-TREAT study led by Arie Levine and colleagues from Israel.

ClinCom's activities also include collaboration with other ECCO Committees on cross cutting themes in clinical research. This included development of ECCO pathogenesis workshops with the Scientific Committee of ECCO (SciCom) such as the highly cited pathogenesis workshop on colorectal cancer. ClinCom Members contributed to the ECCO Topical



ECCO'19 Copenhagen: 3rd School for Clinical Trialists

Review on exit strategies in IBD therapies which generated further research hypothesis and further investigator-initiated studies. To harmonise data collection epidemiological clinical research, ClinCom started working with the Epidemiological Committee (EpiCom) to develop an ECCO Position Statement on Core Outcome Set for Real-World Data Collection in IBD.

ClinCom also is involved in developing the next generation of researchers and provides advice and mentoring for Y-ECCO, particularly in the development of Y-ECCO surveys. Here, young IBD clinicians develop surveys on common clinical scenarios that are promoted by ClinCom and are distributed during the ECCO Congresses. These surveys have led to high-impact publications with trainees as lead authors and have led to further research based on survey results.

Another initiative under the umbrella of ECCO was the development of the ECCO CONFER initiative. This was the brainchild of Shomron

Ben-Horin, who developed a platform for ECCO Members to report exceptionally rare cases as a SciCom Member. Since then, open calls are made to ECCO Members to suggest uncommon cases that require consultation through a collaborative network. Submissions are now evaluated and improved by the CONFER Taskforce under the guidance of ClinCom. Collection of cases from national networks has been hugely successful and has helped reveal patterns and thereby advance knowledge in uncommon cases, from rare manifestations to rare drug toxicities. The CONFER series have thus far generated seven publications in the Journal of Crohn's and Colitis.

As we look back while celebrating the 20th anniversary of ECCO, ClinCom, as one of the key ECCO Committees, has grown in its influence and impact within the IBD Community. The activities of ClinCom continue to promote excellence in clinical research within the ECCO Family.

Shaji Sebastian

From D-ECCO Working Group to the committee

D-ECCO

Background and D-ECCO mission

IBD Dietitians are integral members of the IBD multidisciplinary team. They act as the specialist nutritional advocate for their patients throughout their lifetime and at various stages of their disease. They provide nutritional assessment and support, dietary therapy, and treatment. They are uniquely positioned to lead on research and education on the important role of diet in IBD.

Dietitians have only more recently been active members of the ECCO Community. In 2014, Arie Levine [paediatric gastroenterologist] and Rotem Sigall-Boneh [dietitian], both from Israel, approached ECCO to consider inviting dietitians into the organisation and into the IBD Community. Their initial approach was soon followed by an invitation to meet ECCO Presidents Severine Vermeire and Julian Panes in Vienna. This meeting led to the opportunity to establish a dietitian working group, the D-ECCO WG. The D-ECCO WG was set up to include at most one physician with an interest in diet and nutrition and four dietitians with clinical or research experience [or both] in IBD.

The initial mission for the D-ECCO WG was to 'be dedicated to education, training, research and guidelines for individuals involved in the role of diet in IBD. This will include dietitians and other health professionals/scientists interested in diet and nutrition.' The vision of D-ECCO was that dietitians will be the cornerstone professionals of dietary therapy in IBD.

One of the initial but enduring challenges for D-ECCO has been variations in the role of the

dietitian internationally. Many clinical sites still do not have a dedicated IBD dietitian; physicians lead the nutritional aspects of patient care at such sites. With all the D-ECCO faculty members coming from established specialist IBD roles, education and promotion of specialist IBD Dietitians were at the core of their mission.

Today, the mission of the D-ECCO Committee has evolved to:

- Improve understanding of dietary therapy among physicians and dietitians
- Support and facilitate research of diet and its role in the pathogenesis and treatment of IBD
- Increase participation of IBD Dietitians in ECCO
- Increase the number of IBD centres that have a dedicated IBD Dietitian

D-ECCO evolution from working group to a committee

In 2015, Arie Levine and Rotem Sigall-Boneh assembled an international panel of dietitians with a wealth of IBD-specific research and clinical experience, including Konstantinos [Kostas] Gerasimidis [Scotland], Miranda Lomer [England], and Nicolette Wierdsma [The Netherlands] as founding members of D-ECCO. The first meeting of the founding members of D-ECCO was held at the 10th ECCO Congress in Barcelona in 2015.

The 11th Congress of ECCO in Amsterdam was the first occasion in which dietitians were formally represented at an ECCO Congress; over 150 delegates, mostly dietitians, registered for the first D-ECCO Workshop. Over the last 4

years, the D-ECCO Workshop has had increasing attendance not by only dietitians but also researchers, gastroenterologists, colorectal surgeons, and IBD Nurses. Currently, there are over 300 dietitians in the ECCO communication database, with about 50 dietitians registered as ECCO Members.

In recognition of the high-quality activities and publications [see further details in the next section] that D-ECCO has achieved to date, the working group was officially made an ECCO Committee in 2018. D-ECCO is now established as an important and integral part of ECCO.

During 2018 and 2019, the founding working group members stepped down and new members with IBD research or clinical experience joined D-ECCO. The current D-ECCO Members are Marjo Campmans-Kuijpers [dietitian, The Netherlands; D-ECCO Chair], Catherine Wall [dietitian, New Zealand], Dearbhaile O'Hanlon [dietitian, England], Lihi Godny [dietitian, Israel], and Eytan Wine [paediatric gastroenterologist, Canada].

Activities and Publications

The D-ECCO Committee aims to improve ECCO Members' understanding of dietary therapies and the role and expertise of dietitians in the management of IBD. D-ECCO has disseminated its messages and expanded its reach through various types of publications and collaborative efforts with other ECCO Committees. D-ECCO activities include an annual nutrition and diet workshop, workshops in collaboration with other ECCO Committees, ECCO News articles, interactive continuing education, and a Travel Award.

The D-ECCO workshop, which occurs annually at the ECCO Congress, has comprehensively

addressed different aspects of IBD nutrition and dietary therapy from basic science to clinical practice. The workshop utilises experts in the field to not only present the latest science but also the practicalities of implementing this science into clinical practice. The workshop format includes presentations, an interactive session, panel discussions, debates, case-study presentations, or combinations thereof. Over the last five years, the reputation of the D-ECCO Workshop has grown and in 2020 it was attended by 58 dietitians, gastroenterologists, surgeons, scientists, and IBD nurses.

Since 2019, 10 seats are reserved for dietitians in the N-ECCO School full-day workshop at the ECCO Congress. The workshop is led by N-ECCO and is co-chaired by D-ECCO and has become an opportunity for collaboration between N-ECCO and D-ECCO. The workshop includes two sessions on nutritional assessment and dietary therapy in IBD. The N-ECCO School provides nurses and up to 10 dietitians the opportunity to learn the fundamentals of IBD management. It is the first step for nurses and dietitians who would like to become an IBD specialist.

Every season, a D-ECCO Committee Member writes an ECCO News article on a diet-related subject. These articles are focused on specific topics of interest related to diet in IBD or are Workshop summaries. Examples of recent articles include Nutritional Management of Iron Deficiency; Telemedicine in IBD: My IBD Coach; The Role of the Dietitian in the IBD Multidisciplinary Team; and Nutritional Management in Patients after Pouch Surgery. These articles enable D-ECCO to highlight the role and the expertise of IBD Dietitians while presenting the latest science in nutrition and dietary management in IBD.



ECCO'19 Copenhagen: 4th D-ECCO Workshop

The ECCO Website has many interactive continuing education opportunities. D-ECCO has created three Talking Head videos entitled 'The use of Dietary Therapy in IBD', 'Nutritional assessment in IBD Patients' and 'Active CD: what should we advise our patients to eat'. The Talking Head videos focus more on practical advice and are aimed at sharing clinical experience.

Since 2019, D-ECCO has offered members the opportunity to apply for a D-ECCO Travel Award. This award grants one dietitian the opportunity to visit a different European IBD Centre to observe and learn how another centre uses and implements nutrition and dietary therapies in patients with IBD. This award allows D-ECCO to expand its reach and develop the next generation of IBD Dietitian leaders.

The second mission statement of D-ECCO is support and facilitate research of diet and its role in pathogenesis and treatment of IBD. To help D-ECCO achieve this mission and to stimulate further nutritional scientific research,

in 2019 D-ECCO created the best nutritional abstract award. The winning author is awarded an oral presentation at the annual D-ECCO Workshop.

The greatest effort of D-ECCO has gone into two published Topical Reviews. The first review, Research Gaps in Diet and Nutrition in Inflammatory Bowel Disease. A Topical Review by D-ECCO Working Group [Dietitians of ECCO], published in JCC in 2017, identified central themes related to the role and management of diet in IBD and described the top priorities for future research. Together, 23 research gaps were identified in the fields of aetiologic role of diet, diet as a therapy, and assessment/support. In 2020, the second Topical Review was published. Perioperative Dietary Therapy in Inflammatory Bowel Disease was a collaborative effort between D-ECCO and S-ECCO and identified 26 practice points on dietary assessment and management in the perioperative period in IBD, all highlighting the importance of dietary management in improving patient outcomes.



ECCO'20 Vienna: 5th D-ECCO Workshop

D-ECCO Members have also contributed to ECCO-wide publications, including the 2020 ECCO Position Statement on Quality Standards of Care.

The multifaceted learning experiences promoted by D-ECCO encourages participants and any ECCO Member interested in diet and its role and effect in IBD to expand their knowledge and embark on research in these topics.

Future directions

D-ECCO has made significant progress to date with its mission statements, but there is still much work to be done. Patient access to IBD-trained or specialist IBD Dietitians still varies greatly across Europe. Even in countries that do have some specialist IBD Dietitians, there is inequality of access within these countries. Each year the D-ECCO Workshop has more attendees and there is an increasing number of nutrition-related scientific abstracts submitted to the annual ECCO Congress and to the D-ECCO Workshop. These trends are encouraging and

suggest that there is increasing interest from dietitians, IBD clinicians, and researchers in nutrition and dietary therapy in IBD.

Dietitians contribute a unique perspective to both patient clinical management and IBD research. D-ECCO supports greater diversity of health professionals in the care of all patients with IBD. Such a model of care enables us to treat our patients with IBD more holistically and to improve patient medical, surgical, and, ultimately, quality-of-life outcomes.

Over the next decade D-ECCO has lofty ambitions. We aim to:

- Further highlight and define the role of the dietitian in the management of IBD
- Support and nurture dietitians to understand, and actively contribute to, IBD research
- Improve patient access to IBD-trained dietitians across Europe

Marjo Campmans-Kuijpers

EduCom

ECCO's global influence as an Inflammatory Bowel Disease [IBD] society has increased rapidly over the past decade. Increasing emphasis has been placed on medical education and improvement in patient care at the local, European, and global levels; this has been significantly promoted and led by the EduCom Members and activities.

Ever since its foundation in 2001, ECCO has sought to introduce young and promising gastroenterologists into the complex world of the pathogenesis, diagnosis, and management of IBD while bringing them together either as national groups or individuals. The initial idea of organizing an 'ECCO Course' arose at an early meeting of the ECCO Governing Board and Committees. The first course was targeted at young gastroenterologists interested in IBD. The goal was and remains to expose, teach, educate and discuss all pertinent topics in the field of IBD. The value of such a course was immediately recognised and it was agreed to organise the first 'ECCO Course on IBD for Junior Gastroenterologists' in 2003 in Prague. The course content included lectures [ranging from basic science to diagnosis and management] combined with a discussion of clinical cases.

Since that time and over the past decade, this course is offered on a yearly basis although its name has changed and is now called the 'ECCO IBD Intensive Course for Trainees'. This course has achieved great success and prestige over Europe and

throughout the world. The number of selected attendees has reached 100 per year [still limited to 2-3 participants per country]. Attendees have come from over 40 different countries and the course includes participants from outside Europe. In recent years, the teaching methods have become more interactive and personalised and targeted accordingly for the younger generation. The course is based on structured discussions in small groups [round table] or break-out workshops. To save time, the 'traditional' pre- and post-course multiple-choice exam has now been replaced with an online voting onsite via the ECCO IBD App. The questions are still used to facilitate a more interactive question-and-answer session at the end of each talk. The goals remain to get the most out of the teachers in terms of practical management of IBD cases and medications and to encourage students to learn and to ask 'what they always wanted to know about IBD but never dared to ask'. This spirit has led to a very



Educational Workshop'12: Japan, Tokyo



ECCO'16 Amsterdam: 3rd Ultrasound Workshop

high level of satisfaction among students [rated 4.73 over 5 in 2020]. We also acknowledge the impact and contribution of the devoted faculty members.

Recently, additional courses and workshops have been developed by the EduCom Members. The ECCO Basic Imaging Workshop, as a collaboration with ESGAR, has introduced colleagues from around the world in a hands-on setting to the use of intestinal ultrasound as a monitoring tool for IBD. The workshop has also brought together gastroenterologists with radiologists, with the latter teaching the use of MRI in IBD interactively on workstations. The endoscopy section of the ECCO Basic Imaging workshop has introduced interactive lectures and videos of real-life clinical cases and has provided cutting-edge information and skills on IBD endoscopy. The international faculty has enhanced the course by bringing diverse expertise and techniques in the field from around the world. The course has been enthusiastically received and frequently

requested in recent years. Due to space limitations, we have decided to expand and offer the opportunity for more participants to attend. The growing interest in intestinal ultrasound has been met by ECCO with an additional Advanced ECCO Ultrasound Workshop in collaboration with ESGAR. Lastly, in 2021 the first edition of the ECCO Postgraduate Course in IBD took place at the ECCO'21 Virtual Congress.

To advance education on a global level, between 2007 to 2019 EduCom has promoted 65 educational workshops on four

different continents while engaging with local IBD leaders and societies. In this setting, an ECCO Officer associated with an EduCom Member provide education to ECCO Members on up-to-date subjects based on the ECCO IBD Curriculum [consisting of essential IBD knowledge] and recent publications from ECCO Guidelines. These educators travel around the world to attend three to four workshops in Europe and one to two worldwide every year. The workshops prioritise local attendees' interaction with ECCO Officers and most events are linked to National Societies meetings of the host country. The educational workshops are highly appreciated and have been developed even further in recent years to reach more remote locations.

Given the current COVID-19 pandemic, which poses obvious obstacles to these workshops, EduCom is about to launch a series of virtual workshops that will be coordinated with local IBD leaders in different countries. In parallel, EduCom is disseminating knowledge online by different virtual platforms. Both the e-CCO

Learning and ECCO e-Guide are receiving increased attention. EduCom is involved in the development of online educational content within the ECCO e-Learning Taskforce. In the ECCO e-Guide, a flowchart covering the management of IBD patients was developed and is regularly updated according to ECCO Guidelines. On the e-CCO Learning platform, extensive educational material based on recorded congress talks, case-based learning slides, videos, and podcasts are made available in the ECCO e-Library, thus facilitating dissemination of this knowledge.

Finally, EduCom's activities are also available in the format of academic publications. In 2017, the EduCom together with a large panel of experts from Europe and around the world developed the ECCO IBD Curriculum that was published in the Journal of Crohn's and Colitis [JCC]. The Curriculum is an expert statement that defines what gastroenterologists need to know to be considered IBD experts. It is a benchmark for ECCO educational content against a definitive

list of knowledge requirements; an index of the e-CCO online content and a tool that can be used by national physicians' societies; and a guide for future education paths for individual physicians. This Curriculum is reviewed and updated on a yearly basis in an EduCom meeting and is published on the e-CCO Learning Platform. Most recently, EduCom members in collaboration with S-ECCO and H-ECCO Members were involved in creating a Topical Review [TR] that is focused optimizing reporting in three pertinent fields in IBD management [endoscopy, histology, and surgery].

In summary, the combination of initiatives, courses, workshops with different scientific activities, and the e-CCO Learning Platform have helped to advance global education in IBD and to position ECCO as a leading international IBD society.

Christian Maaser, Marietta Iacucci, Paulo Kotze, Henit Yanai, Pierre Ellul & Konstantinos Karmiris



ECCO'19 Copenhagen: 1st Basic Imaging Workshop Endoscopy

EpiCom

The Epidemiological Committee of ECCO [EpiCom] was founded in 2007 on the legacy of the European collaborative study on Inflammatory Bowel Disease [EC-IBD], which was one of the first European networks that sought to improve knowledge on IBD epidemiology using high-quality methodology. The EC-IBD was a great foundation upon which EpiCom was able to grow and accommodate the changes in conducting epidemiology studies in IBD. In recent decades, epidemiology has expanded dramatically by building and implementing scientific projects of greater complexity in the era of big data, precision medicine, integration of multi-level data, real-world data, and causal inference. Since the beginning of EpiCom, one of its main activities is to provide expert knowledge on different aspects of epidemiology through educational workshops. These workshops are

held every 2 years at the ECCO Congress and have been developed for physicians, surgeons, pediatricians, and IBD Nurses. Every workshop includes an interactive session based on either question-and-answer sessions, clinical-case discussions, or group sessions during which participants are involved in the design and interpretation of epidemiology studies.

The first EpiCom Workshop took place in 2012 during the 7th Congress of ECCO in Barcelona and was focused on the creation and design of an epidemiology study, based on the example of the EpiCom inception cohort. The second and third EpiCom Workshops were focused on the implementation of epidemiology findings into clinical practice, from cancer risk in IBD to the impact of environmental factors. Recently, due to access to new data sources and development of complex methodological approaches, research



ECCO'16 Amsterdam: 3rd EpiCom Workshop



ECCO'20: 5th EpiCom Workshop

in pharmacoepidemiology has dramatically increased. While this evolution has allowed us to move from real-world data to robust real-world evidence, it may be challenging to implement these methods and to interpret the findings obtained. The fourth EpiCom Workshop aimed to provide knowledge and understanding of the main pharmacoepidemiological methods. The various types of data sources available to perform pharmacoepidemiology studies were summarised, from prospective real-world trials to nationwide healthcare administrative databases. The main methodological approaches were also described along with their strengths and weaknesses. In addition to the types of data sources and methodological approaches, new study endpoints have emerged in recent years. The fifth EpiCom Workshop, which took place in 2020 during the 15th ECCO Congress in Vienna, was focused on patient-reported outcomes and its implementation in research and clinical practice. Patients diagnosed with IBD shared their

experience of using patient-reported outcomes in a real-life setting, and participants were asked to implement patient-reported outcomes in the following hypothetical settings: clinical practice, clinical trials, and regulatory approval. The sixth EpiCom Workshop will take place in 2022 during the 17th ECCO Congress in Vienna and will be focused on risk assessment and outcome prediction in IBD.

The EpiCom inception cohort, whose aim was to investigate the occurrence, disease course, treatment strategies, and prognosis of IBD patients in Europe, is thus far one of the main achievements of EpiCom in terms of scientific publications. Following a kick-off meeting in Vienna in 2006 and an announcement in the ECCO eNewsletter, 31 centres from 14 Western and eight Eastern European countries participated in the cohort. More than 1500 patients recently diagnosed with IBD were ultimately included. This cohort provided important findings on treatment strategies

according to European countries and led to several major publications. One of the major findings was the first identification of a West-East gradient in IBD incidence in Europe. To clearly distinguish between promotional support for research by ECCO in contrast to actual studies taking place outside of ECCO, this cohort was renamed in 2017 to the Epi-IBD Study Group. Since then, this group has also undertaken repeated efforts to use UR-CARE for their study projects.

EpiCom also promotes cross-national research on IBD in Europe through the UR-CARE database, which is an online international platform for collection of IBD patient data for daily clinical practice and research studies. EpiCom was involved in the UR-CARE Taskforce, which designed the architecture of UR-CARE from 2014 to 2016. The UR-CARE platform is now open to all clinicians and IBD centres in Europe and allows for collaborative research projects. A critical aspect of collaborative research projects is the interoperability of different datasets. The Epidemiological Committee supports the FAIR data principles, which provide guidelines to improve the Findability, Accessibility,

Interoperability, and Reuse of datasets. The FAIR data principles were summarised by EpiCom in a Talking Heads video posted on the e-CCO Learning Platform in 2019 and also in a Skills Video in 2020.

In 2015, EpiCom conducted a survey with the aim of identifying which research registries and datasets are already available across Europe and how these can best be accessed. ECCO National Representatives from each of the 36 ECCO Country Members, plus Luxembourg and Iceland, were asked to complete a questionnaire requesting information about registries within their country. The findings were published in 2017 in the *Journal of Crohn's and Colitis*. EpiCom was also involved in several ECCO Guidelines and Topical Reviews, notably the Topical Review on environmental factors in IBD published in 2017. Recently, a joint collaborative project between EpiCom and the ECCO Clinical Research Committee [ClinCom] was launched to develop a core outcome set in real-world studies in IBD. This will lead to the publication of an ECCO Position Statement in the near future.

One of the greatest aspects of research is its collaborative approach, which may be the starting point of valuable friendships. We are happy to support the development of research collaboration in the IBD Community and are grateful for the fantastic work that has been done thanks to the cooperation of so many hard-working people.

Valerie Pittet



ECCO'16 Copenhagen 2nd EpiCom Workshop

GuiCom



2019 UC Kick-off

The Guidelines projects were some of the first activities of ECCO and the Guidelines Committee (GuiCom) remains one of ECCO's busiest. Central to the mission of ECCO is to improve quality of care in IBD, and a key mechanism for this comes through the generation and publication of high-quality guidelines addressing all aspects of IBD management.

GuiCom is also one of the Committees that best represents the ECCO Spirit, by fostering diversity and at the same time bringing people together. In contrast to other international organisations, where guideline participation is often restricted to a small cadre of key IBD leaders, GuiCom encourages all ECCO Members to apply for participation in guideline projects, with specific places reserved on every call for rising stars coming up through the Y-ECCO ranks.

During the past decade of growth, a key challenge has been for the GuiCom to adapt and diversify to use a wider range of

guideline-writing methodologies. When considering new projects, GuiCom must first assess the clinical importance of a given topic, the available resources to dedicate to the project, the project timelines, and, of course, what is known about the quality and depth of available evidence. On one hand, for the most important topics and where the data will support detailed scrutiny and debate, we can seek to commit resources to generate the very highest possible quality of guidelines through the use of the GRADE process [see below]. At the same time, through the development and expansion of Topical Reviews since 2016, we retain the flexibility to generate timely and clinically useful material in more niche areas. Topical Reviews are promoted by the GuiCom or can be proposed by other Committees and produced with the assistance of GuiCom.

The intense activity of GuiCom is reflected in the increasing number and importance of ECCO manuscripts. Since their beginning,



2019 CD Consensus Meeting

ECCO Guidelines have received an average of 300 citations and over an average of 45 000 downloads, and Topical Reviews have received an average of 30 citations and over an average of 6,500 downloads. Of course, we would not have been able to accomplish this without the tireless work behind the scenes of the committed ECCO Office Team.

From Oxford to GRADE

With growth comes maturity, and for GuiCom this has meant a drive to increase quality and accountability in guideline generation. All persons involved are aware that this has been a challenging process that came with many growing pains and lively discussions.

The first ECCO Guidelines on the medical treatment of CD and UC were developed using an approach to literature review and evidence scoring based upon the Oxford Centre for Evidence-Based Medicine: Levels of Evidence. This approach has limitations that we all became increasingly aware of. Importantly, we

found the need for a structured and systematic literature search and a systematic approach to assessing quality based not only upon the type of study used but also on the individual qualities of each study identified.

Ultimately, GuiCom, with the support from the ECCO Governing Board, decided to pilot the use of a new methodology for what became the 2019 Crohn's Disease Guidelines. The Grading of Recommendations, Assessment, Development and Evaluations [GRADE] Methodology represents a systematic approach to making judgements about the quality of evidence and strength of recommendations. GRADE is now widely seen as the most effective method of linking evidence-quality evaluations to clinical recommendations and is used by many international societies. While we believe that the effort to implement GRADE Methodology into our guidelines represented a step towards quality and methodological rigor, this also required considerable effort and dedication. The GRADE Methodology requires a complex

process to identify clinically relevant questions, to formulate appropriate PICO questions, and to perform an exhaustive and accurate literature search to support the final statements strictly based on the level of evidence derived from the literature search.

To embark on this new approach, a huge amount of work and commitment was required. GuiCom Members and all guideline participants had workshops and training by a team of methodologists led by Stefanos Bonovas, who was always patient to explain the rationale and the logic behind the process. To support this, GuiCom launched a series of workshops that were focused around the annual ECCO Congress but also included some stand-alone dedicated training. These workshops were all aimed at increasing awareness and practical experience of the available guideline methodologies and the importance of the principles underlying this process amongst members of the ECCO Community.

In contrast to previous guidelines, where participants met only at the end of the process to vote on proposed statements, GRADE Guidelines started with a meeting to decide and vote on the relevant outcomes. Importantly, patient representatives were involved in this process from the outset, lending a valuable perspective particularly on the selection of key questions and outcomes of interest. We must say that the participation of patients from EFCCA made the whole process more meaningful.

The thoroughness demanded by the GRADE Methodology and the difficulty we sometimes encountered in formulating clinically useful advice in the absence of properly conducted randomised clinical trials made us realise that

GRADE was also not the Holy Grail for all types of guidelines that GuiCom wants to develop. In particular, in some cases [such as guidelines affecting surgical practice] we strongly felt that the lack of high-quality evidence could not and should not preclude the development of recommendations much needed by clinicians. We all know that the most difficult decisions we face daily have not been studied in the setting of a clinical trial, and that all the expertise and experience sharing that GuiCom promotes should be leveraged and capitalised upon. For this reason, GuiCom has not abandoned the Oxford methodology in these instances. In such instances, a more narrative approach is permitted that is supported by a careful but undeniably less rigorous approach to evidence scoring. Nonetheless, we have been careful to ensure that the lessons learned from the GRADE process have influenced, where possible, our use of the Oxford methodology. For example, this includes careful prior formulation of questions of interest, such as patient representation and documented literature searches by a professional librarian.

To continue promoting education in guideline development, GuiCom organised for the first time in 2019 the GuiCom Workshop to debate and discuss the process of developing guidelines, to explain the key differences between different methodologies, and to start preparing the next generation!

Ultimately, 10 years on, ECCO can now boast not just one, but three different formats of high-quality guidelines – a pyramid [if you like] with GRADE Guidelines at the top, guidelines developed using Oxford methodology in the middle, and the Topical Review series supporting the base.

Joana Torres & Tim Raine

H-ECCO

How it all began

The Committee of Histopathologists of ECCO [H-ECCO] is one of the newest. H-ECCO started in 2014 as a working group under the lead of Cord Langner and included Vincenzo Villanacci, Roger Feakins, Paula Borralho-Nunes, and Magali Svrcek. H-ECCO received official approval from the ECCO Governing Board in 2018 and has been focused on the future from its start. Pronunciation of its abbreviation, 'H-ECCO', requires emphasis on the 'H'.

Almost a century ago, histopathologists contributed to the initial discovery of IBD as a disease that was distinct from other disorders, such as certain infections. Later, when IBD patients were recognised and treated earlier in their disease course, we increasingly gained experience with surgical tissue specimens from IBD patients. We have thus been able to continuously evaluate and improve our criteria for diagnosing and classifying IBD. We have learned to distinguish Crohn's Disease

[CD] of the colon from Ulcerative Colitis [UC] and to recognise that a small minority of IBD cases may not be immediately classifiable as CD or UC, even in surgical specimens [i.e. indeterminate colitis].

The increasing application of endoscopy has led us to redefine our diagnostic criteria to make them applicable to the very small biopsies obtained by this approach. We have recognised the importance of obtaining sufficient clinical and endoscopic information prior to the microscopic evaluation of such material. We have emphasised the importance of the number of biopsies taken for making a correct diagnosis. Our role in the evaluation of such biopsies has also expanded, from assisting with the initial differential diagnosis to distinguishing disease flares from various infectious complications and recognizing adverse drug reactions. We now know that IBD may make its first presentation in young children and also in elderly people, and that the disease may then follow an atypical course.

The recent past

The continuing proliferation and sophistication of endoscopic tools and techniques has had a major positive impact on our ability to recognise preneoplastic lesions and early cancers in IBD. The increasing number of biopsies from such lesions also enables us to classify them in more detail microscopically and to expand the studies on the molecular genetic changes that they may harbour.



ECCO'16 Amsterdam: 1st H-ECCO IBD Masterclass



ECCO'19 Copenhagen: 4th H-ECCO IBD Masterclass

In the last decade, there has been a resurgence of interest in histopathologists' contribution to the grading of IBD activity, mainly in UC. At first, this was largely driven by the pharmaceutical industry and most of the efforts in this research field were applied to endoscopic biopsies obtained during clinical trials. Many different pathologists had previously published various histological indices for IBD activity to assist clinicians in medical management. Therefore, the choice of which index to apply in a particular clinical trial is not always straightforward. In fact, new indices have recently been developed based on concerted efforts of teams of pathologists, clinicians, basic researchers, statisticians, and others. Histological indices have been tested for performance and have been validated on large numbers of biopsies by comparing their features with the recorded clinical and endoscopic data. These indices have also been cross-validated against each another and against biochemical parameters of IBD activity. We are now close to a point where simple, robust, and easy-to-use UC histological

indices can be introduced into daily clinical practice. We hope that these indices will assist our clinical colleagues in their daily decision making on the timing of therapy initiation, the optimal therapy choice for each patient, and the planning of when and how to follow up patients who are in clinical and endoscopic remission.

Still more recently, there has been a resurgence of active research into the nature, development, and progression of fibrosis and stenosis in CD and its relationship with ongoing inflammation and various potential therapeutic interventions. Such studies are again team efforts and the involvement of basic scientists and molecular and computational biologists is very important. Evidently, it would be a major advantage to many CD patients if the development of fibrosis could be recognised early and halted or slowed from its onset.

Inevitably, there is great variation within Europe regarding support for pathology services. H-ECCO had several aims from its outset. The



ECCO'20 Vienna: 5th H-ECCO IBD Masterclass

most important was to improve the quality of IBD histopathology wherever possible. There are many possible approaches to achieving this aim, such as organizing continuing medical education, providing support for guideline composition, collaborating with other ECCO Committees, and involvement in clinical management initiatives. From the beginning, H-ECCO strongly supported education and was given the opportunity to organise an annual H-ECCO IBD Masterclass. Despite its specialised nature, the event was and remains very successful. Excellent international speakers, including histopathologists, scientists, and clinicians, have been part of the programme every year. The H-ECCO Committee Members also contribute to many other ECCO projects, including Topical Reviews and Position Statements.

ECCO has a robust system of committee turnover, which ensures the involvement of people of different ages and professional backgrounds. At first, regular replacement of H-ECCO Committee Members on this basis was not always easy. However, as awareness of the importance of histopathology at ECCO increased, considerably more pathologists

showed an interest not only in membership on the H-ECCO Committee but also in other ECCO activities. Current H-ECCO Members are now continuing the work of their esteemed predecessors and are trying to engage even more pathologists for ECCO's work. There is already a healthy competition for Committee seats, and we wish to thank the prospective candidate members for their continued interest throughout the COVID-19 pandemic. We also expressly want

to state that ECCO's support for all specialties in IBD is highly commendable and is one reason why the organisation contributes greatly to the improvement of IBD services globally.

H-ECCO will continue to provide their expertise for all ECCO activities and to promote better understanding and cooperation between histopathologists and IBD clinicians. We will do so by means of our continuing annual H-ECCO IBD Masterclasses and our participation in various working groups and publication projects. The Committee Members would also like to thank the European Society of Pathology [ESP] for its continuing support and are enthusiastic about further joint collaborative sessions with the ESP at the European Congress of Pathology.

Finally, the current H-ECCO Committee Members once again want to use this occasion to thank our predecessors, Roger, Vincenzo, Paula, and Magali, for all their efforts in H-ECCO over the past years, for the pleasant cooperation we have had, and for their continuing encouragement and support.

Gert de Hertogh & Roger Feakins

The N-ECCO Committee in the last 10 years

Overall evolution since the launch of the committee

If IBD Nurses are to become equal partners in the multidisciplinary team and to meaningfully contribute to the improvement of standard of care across Europe, they need access to IBD education. N-ECCO Committee, through its range of activities strives to help IBD Nurses to become proactive and innovative thinkers, so that IBD Nurses will be actively involved in developing new services and improving patient care.

N-ECCO Committee aims are to improve access to nurse education in IBD and to provide networking opportunities for national nursing organisations throughout Europe. Since the launch of N-ECCO in 2007, the IBD nursing "family" has grown and developed. Year after year, the number of Nurse Members in ECCO has increased significantly and continues its steady growth. IBD Nurses in Europe have made

substantial progress over the last ten years. This can be seen by the increasing number of nurses attending the ECCO Congress and the number and quality of submitted nurse abstracts.

Today, N-ECCO is a very active committee with three educational courses at the ECCO Congress, including the N-ECCO Network Meeting, the N-ECCO School and the N-ECCO Research Forum.

At the outset of N-ECCO, the Network Meeting was the main activity for IBD Nurses. This annual meeting has now become an integral part of the ECCO Congress and is an opportunity for IBD Nurses from around the world to present their developments from research and clinical practice and hear from speakers on topical issues on IBD care developments.

Over time the range of activities run by the N-ECCO Committee has expanded. At the ECCO

Congress in Prague, 2010, the N-ECCO Committee introduced a new educational activity, in the form of N-ECCO School, tailored to IBD Nurses training needs. With this new initiative, ECCO has given young nurses, who might still be in training and have an interest in IBD, the possibility to attend an IBD-focused course every year. The N-ECCO School takes place as a one-day course and consists of lectures and workshops from nurses, dietitians, and physicians.



IBD Nurse Educational programme 1st Meeting – Italy

In 2014, N-ECCO introduced an additional educational activity for IBD Nurses, the N-ECCO Research Forum, which is held every other year. The aim of the Research Forum is to build research capacity and provide a platform for novice and experienced researchers to network and plan joint research.

In several European countries, IBD Nurses have now become integral members of multidisciplinary teams, involved in decision-making in patient care and care provision. To accelerate the training of IBD Nurses across Europe, N-ECCO Committee instigated the development of IBD Nurse Education Programme.

After years of planning and collaborative work, the latest activity that N-ECCO introduced in 2018 is the IBD Nurse Education Programme. The aim of the Programme is to increase the number of IBD Nurses and to enhance their role by developing knowledge and skills. The programme is run in one country at the time, over a 6-month period. Sessions are delivered by face-to-face teaching and distance learning, using e-Learning resources. The first cycle took

place in Italy. The second cycle was planned to start in 2021, was unfortunately affected by COVID-19 pandemic.

N-ECCO Committee plans and coordinates the development of educational e-Learning resources for IBD Nurse Members. The goal is to develop e-Learning activities like Talking Heads and Audio Podcasts, following the structure of the IBD Curriculum on one hand and the N-ECCO Consensus Statement on the other. This work will start in 2021.

N-ECCO Awards

Every year N-ECCO awards the N-ECCO Research and Travel Grants. Several studies have been funded by N-ECCO through the N-ECCO Research Grant since the start of this initiative in 2017. IBD Nurses, academic and clinical researchers from different countries have worked together on international research projects.

The N-ECCO Travel Award has allowed several nurses to travel to other countries or IBD centres in their own country, to learn new clinical practices from other IBD Nurses. The N-ECCO

National Representatives play an important role in acting as the link in their own countries for all IBD Nurses.

N-ECCO's most important activity – fostering the role of IBD Nurse

The N-ECCO Committee has undertaken many activities over the last ten years. These activities cover both clinical practice, academic and clinical research, which positively contribute to the improvement and development of IBD care in Europe.



IBD Nurse Educational programme 2nd Meeting – Italy



N-ECCO School group picture

Out of these, the most notable is the continuing development of the IBD Nurses' role.

N-ECCO most important publications

The best way of sharing innovation and disseminating new knowledge is by publication, so that nurses all around the world can benefit and implement the new discoveries to improve patient care. The most significant publication led by the N-ECCO Committee is the N-ECCO Consensus Statement on the European Nursing Roles in Caring for Patients with Crohn's Disease or Ulcerative Colitis, first published in 2013 and updated in 2018. The document incorporates the most up to date evidence and provides guidance for IBD nursing care and the required standard, whilst acknowledging the variety of IBD nursing practice across Europe.

Outlook

N-ECCO Committee celebrates the achievements thus far. At the same time, we recognise that more work needs to be done, if the quality of care for people with IBD and

their quality of life of living with the condition are to continue to improve. The Committee will continue its important work to educate IBD Nurses across Europe and to support nurses in developing their specialist role.

The aim is to identify the gaps and refine and expand the work undertaken through the N-ECCO Network Meetings, the N-ECCO School, the N-ECCO Research Forum, and the IBD Nurse Education Programme. We are always looking for new talent, nurses with energy and enthusiasm to join our Committee and to bring new ideas to work for the benefit of patients with IBD and IBD Nurses' community in Europe and beyond.

Susanna Jäghult, Ana Ibarra, Wladzia Czuber-Dochan, Miriam Ganon & Petra Hartmann

P-ECCO

P-ECCO mission

- *Improve knowledge on paediatric-specific IBD issues*
- *Support and facilitate research into paediatric IBD*
- *Interact with the Porto IBD WG of ESPGHAN*

Why do we need P-ECCO?

The Paediatricians of ECCO (P-ECCO) Committee will celebrate their first 10 years and also ECCO's 20th anniversary in 2021. The formation of P-ECCO was a vital moment for those caring for children and young people with IBD, and ECCO of course is the natural home for such a paediatric group. Paediatric-onset IBD (P-IBD, diagnosis <17 years as per the Montreal and Paris classifications) comprises approximately 8–9% of incident IBD patients from population-based studies in Europe. However, both paediatric-onset UC and CD have a more extensive location at diagnosis

and a more rapid progression of phenotype than adult-onset IBD. Furthermore, P-IBD occurs at a crucial time for growth, pubertal progression, psychological maturation, and self-esteem in those aged ≥ 10 years. In addition, this is also a time when educational attainment is a priority, as this is the strongest predictor of adult income in employment. P-IBD also occurs in infants and pre-school children (very early-onset IBD [VEO-IBD], onset <6 years), who also have particular physiological and family concerns and have a much higher likelihood of a monogenic (rather than polygenic) cause of IBD. Our P-IBD service design differs from that of adults, as P-IBD care is centred in regional services (or national services in some countries). These services cover large geographical areas, which include hospitals with paediatricians and adult gastroenterologists and so require shared P-IBD care from the P-IBD unit. Further,





ECCO'19 Copenhagen: 6th P-ECCO Educational Course

P-IBD teams are truly multi-disciplinary, with highly prominent and vital roles for IBD Nurses, dietitians, and psychologists.

P-ECCO launch and evolution

The formation of P-ECCO was initiated in 2010 and the first meeting of the committee members was at ECCO 2011 in Dublin. P-ECCO held their first joint Educational Course with N-ECCO at ECCO'19, when our average attendance doubled. Lastly, there have been three ECCO paediatric educational workshops to date (Glasgow, Helsinki, and Antwerp); the fourth was planned for June 2020 in Zagreb but was cancelled due to the COVID-19 pandemic. All the chairs and committee members are immensely grateful to the wonderful support they have received from the ECCO Office over the last 10 years.

Most impactful activity of P-ECCO

P-ECCO realised that paediatric gastroenterologists worldwide with a special

interest in IBD are much rarer than their adult counterparts, thus close collaboration with other groups has been fundamental for P-ECCO. The primary collaboration has been with the Paediatric IBD Porto Group of ESPGHAN (35 members, of whom >90% are ECCO Members and includes all previous, current, and known future P-ECCO chairs). ESPGHAN is the largest PGHAN body in the world, and their IBD Working Group, including the Porto group, has almost 150 members. Joint guidelines and position statements (see below) have been published by ECCO and ESPGHAN, and P-ECCO has also published with PIBDnet (a global group) and the Canadian Children IBD Network.

In terms of inclusivity, P-ECCO Members recognise the vital contributions of our MDT members clinically and academically. We held a joint course at ECCO'19 with N-ECCO and with D-ECCO at ECCO'21, entitled 'Food for thought in IBD'.

Most important publications from P-ECCO

During the period 2010–2020, together with (mostly) European paediatric gastroenterologists, P-ECCO has worked hard to improve P-IBD management through the dissemination of relevant guidelines and other publications.

Paediatric UC management guidelines

In 2011, Dan Turner et al. published a consensus for management of Acute Severe Colitis (ASC) in children, including a management flowchart. This was both a systematic review and a joint statement on behalf of ECCO, ESPGHAN, and the Porto IBD working group of ESPGHAN. ASC occurs more often in children than in adults because of the increased prevalence of extensive colitis. The Paediatric Ulcerative Colitis Activity Index (PUCAI) score was shown to be very helpful in defining disease activity and was advocated for general use, with PUCAI ≥ 65 points a strong indication for immediate hospitalisation. An associated guideline on ambulatory paediatric UC management was developed with ESPGHAN and was published in 2012, including a management flowchart.(2) This guideline emphasised that the choice of treatment for adults is based on both disease severity and extent, whereas in children this choice depends mainly on disease severity since limited distal disease is uncommon.

In 2018, new data regarding management, diagnosis, and outcomes mandated a revision of the UC guidelines in both ASC and ambulatory UC. Highlights in the revised ASC guidelines included advice on the use of thromboprophylaxis and recommendations on sequential therapy and on TDM. Highlights in the ambulatory paper were a prominent role for faecal calprotectin, use of off-label medication (vedolizumab), and the classification algorithm into IBD subclasses based on class 1, 2 or 3 P-IBD features. The latter led to the development of a very helpful app, the IBD classes calculator (supported by the Catherine McEwan Foundation).

Paediatric CD management guidelines

In 2014, the first evidence-based and consensus guideline for paediatric CD was developed by an expert panel of 33 IBD specialists led by Frank Ruemmele within ECCO and ESPGHAN. Children and adolescents with CD often present with a more complicated disease course than adult patients. Impact on growth and pubertal and emotional development of paediatric patients should also be considered. The key role of exclusive enteral nutrition (EEN) for induction of remission was advocated due to its excellent safety profile and noninferiority to prednisolone. Predictors for poor disease outcome (so-called 'POPOs') were introduced (severe perianal fistulizing disease, severe stricturing/penetrating disease, severe growth retardation, panenteric disease, and persistent severe disease).

The paediatric CD guideline was updated in 2020. A key message was the more precise and very early identification of patients at high risk of a complicated disease course to prevent bowel damage, with consideration of up-front anti-TNF therapy combined with an immunomodulator. Close monitoring of treatment response with timely therapy adjustments when targets are not met was emphasised, plus the use of serial faecal calprotectin measurements and timely endoscopic or radiological reassessments.

Transition

In close collaboration with colleagues working in adult IBD, a Topical Review for transitional care in IBD to provide guidance in clinical practice was developed. An established transition programme prevents patients becoming lost to follow up during transfer, promotes adherence, and reduces emergency department visits and surgeries.

Placebo

A statement on the role of placebo in paediatric IBD trials was provided by a collaboration of P-ECCO, ESPGHAN, PIBDnet, and the Canadian children IBD network. The consensus was that placebo should only be used if there was genuine equipoise between treatment and placebo. This is often not the case since the pathophysiology and response to treatments are usually similar between P-IBD and adult IBD.

Outlook

Too many medications are currently prescribed as off-label in children. Most of the evidence for management of P-IBD is based on adult trials, with paediatric modifications following dose-finding or observational studies. There is a long delay before paediatric trials are started, and an even longer delay until such therapies receive regulatory approval. For adult IBD patients, many new drugs with different mechanisms of action are coming to the market. It will be a challenge to facilitate timely, well-designed, clinical drug trials in P-IBD.

P-IBD patients are the adult IBD patients of the future. Bowel damage must be prevented for the sake of P-IBD patients and for their future adult IBD management teams. A crucial task for P-ECCO, strengthened by the experience and support of ECCO, is to ensure that the most vulnerable IBD patients, namely those with paediatric or adolescent onset, can benefit from new developments and insights derived from adult-onset IBD.

David Wilson & Lissy de Ridder



2019 Paediatric CD Consensus in Barcelona

A large, abstract graphic of a blue and white waveform, resembling a sound wave or a data signal, is positioned in the upper half of the image. The waveform is set against a solid orange background. The blue part of the waveform is on the left, and the white part is on the right, creating a sharp contrast.

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Falk Foundation is an independent scientific institution dedicated to promoting the transfer of knowledge in the field of digestive and metabolic medicine. We facilitate scientific exchange and interdisciplinary cooperation at the national and international level through meetings, conferences and symposia. We also publish a comprehensive, up-to-date range of media services (in print and digital form) for healthcare professionals and doctors. Supporting young scientists is another key aim that we promote by donating numerous science prizes.

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An abstract, 3D wireframe rendering of human digestive organs, including the liver, stomach, and intestines, is centered in the upper half of the advertisement. The organs are depicted with glowing, translucent blue and red lines, giving them a futuristic, digital appearance. They are set against a dark blue background with a subtle grid of white dots and a horizontal white light streak passing behind the organs.

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SciCom

Supporting IBD research across Europe

The Scientific Committee [SciCom] of the European Crohn’s and Colitis Organisation [ECCO] was launched in 2004 to provide a formal structure that supports science related to Inflammatory Bowel Diseases [IBD]. Since then, SciCom has developed and evolved considerably; from the early days when a few motivated ECCO Members with a strong interest in research met in the homes of SciCom Members to a clearly defined SciCom structure and regulations; from limited funding opportunities to a sophisticated structure of research support with numerous new funding schemes and educational activities. One of the most important initiatives of SciCom was a new educational activity called the SciCom Workshop, where scientific topics of critical importance to the understanding and treatment of IBD are discussed. This initiative was launched at the ECCO Congress in Vienna 2013 and has since taken place annually, featuring topics ranging from intestinal fibrosis to cell-based therapies and treatment targets in IBD [Table 1]. Over the years, the SciCom

Workshop has held very active discussions between basic scientists and clinicians, fostered collaboration, and served as the starting point for many innovative research projects. Another main initiative of SciCom has been the ECCO Scientific Workshops, which are thinktank activities held every 2 years on a new topic of central interest to IBD. In ECCO Scientific Workshops, a group of dedicated scientists collects and discusses the available literature on a selected topic, considers strategies for future research development, and summarises these findings in ECCO Scientific Workshop Papers published in the Journal of Crohn’s and Colitis. A timeline of the most significant SciCom milestones is depicted in Figure 1.

Arguably the SciCom activity of greatest impact is provision of a framework that supports all aspects of IBD research. Indeed, one of the main goals of ECCO is to encourage, promote, and support visionary, innovative, and interdisciplinary basic or clinical [or both] scientific research in IBD and to foster productive

year	Topic
2013	Intestinal fibrosis
2014	Primary sclerosing cholangitis update forum
2015	Cell-based therapy in IBD
2016	Molecular aetiology of IBD
2017	Methodology on research
2018	Fat in IBD – Much more than an innocent bystander
2019	Mechanisms and therapeutic modulation of mucosal healing in IBD
2020	Similarities and differences in the pathogenesis of immune mediated inflammatory disorders

Table 1. Topics of SciCom Workshops



*One time award supported by the industry via an unrestrictive grant.
 Funding schemes are italicised.

Abbreviations: SciCom: Scientific Committee; ECCO: European Crohn's and Colitis Organization; N-ECCO: Nurses of ECCO; AOCC: Asian Organization for Crohn's and Colitis; D-ECCO: Dietitians of ECCO; IBUS: International Bowel Ultrasound Group.

Figure 1. A timeline of some SciCom milestones

collaboration among European research groups. Parallel to the growth of ECCO, which now comprises not only IBD clinicians and researchers but also nurses, histopathologists, and dietitians, we have seen a continuous expansion of ECCO funding opportunities that reflects this development. Starting with ECCO Grants, which support young IBD scientists in their own groups, or ECCO Fellowships, which provide support for young IBD scientists to join other research teams, ECCO has since continuously expanded its funding schemes [Figure 1]. This includes additional opportunities for travel and exchange among European IBD Centres to observe and learn about scientific techniques or clinical practice in IBD. These opportunities are available not only for clinicians [ECCO Travel Award] but also for nurses [N-ECCO Travel Award] and dietitians [D-ECCO Travel Award]. Moreover, through a collaboration with the

Asian Organisation for Crohn's and Colitis (AOCC), European and Asian investigators now have the opportunity for clinical exchange between European and Asian IBD Centres [ECCO-AOCC Visiting Travel Grant]. In addition to opportunities for travel and exchange, numerous new funding schemes supporting IBD research have been launched in recent years. This includes the N-ECCO Research Grant for IBD Nurses, the ECCO Research Award with focus on observational research projects using the United Registries for Clinical Assessment



ECCO'18 Vienna: ECCO Awards Recipients



ECCO'20 Vienna: 2nd Scientific Workshop

and REsearch [UR-CARE], and the ECCO-IBUS Intestinal Ultrasound Research Grant. In addition, in recent years we have launched the ECCO Pioneer Award and the ECCO Multi-Year Research Grant, which are two highly visible funding schemes that support visionary, interdisciplinary research collaborations in IBD. I personally had the honour and privilege to be a recipient of an ECCO Fellowship Award in 2014 to investigate the mechanisms underlying primary non-response to anti-TNF therapy in patients with IBD at an IBD Centre of Excellence in Leuven, Belgium. This was a great experience that made me better both as a person and as a scientist.

There are numerous high-visibility publications that have been derived from these ECCO initiatives. Among the publications originating from the ECCO Scientific Workshops (www.ecco-ibd.eu/publications/ecco-scientific-workshop-paper), those referring to anti-TNF therapy failures in IBD [published in 2010] and intestinal healing [published in 2014] have had a great impact on IBD clinical practice.

Regarding the ECCO Fellowships and Grants publications, there have already been four articles published in Nature, eight in Gut, three in Gastroenterology, two in Nature Communications, one in Proceedings of the National Academy of Sciences USA, 13 in the Journal of Crohn's and Colitis, and one in Clinical Gastroenterology and Hepatology. This is an impressive record and a clear testimony to the success of ECCO's support of IBD research.

While SciCom has evolved considerably over time, there are things that have remained unchanged over all these years. These are the commitment, enthusiasm, transparency, dedication, and hard work of SciCom Members and the mission of SciCom to promote scientific activities within ECCO, to take responsibility for the scientific programmes of the ECCO Congress, and to stimulate scientific interactions in the ECCO Community and beyond.

Konstantinos Papamichail
on behalf of the SciCom

S-ECCO

Ten years after: The S-ECCO history

The beginning

Almost 10 years after the founding of ECCO, Andre D'Hoore and Willem Bemelman found themselves engaged in an interesting discussion about the multidisciplinary approach in managing IBD. It was at an ECCO conference and after a few drinks at the Hearts and Minds evening they decided that it was time that surgeons became active members of this great ECCO family. After all, the aim of ECCO was the optimisation of IBD patient care in Europe. How would that be possible without dedicated surgeons being involved? Andre and Willem discussed the project several times with the Governing Board and got Johnson and Johnson interested as a sponsor. Unfortunately, the organisation took a while. It was not until a vote for was taken for the new ECCO structure, defended by Daan Hommes, at the UEGW

Barcelona 2010 that made S-ECCO a fact. From now on, surgeons could participate on the operational board of ECCO.

The first masterclass dedicated to the surgical treatment of Crohn's Disease in February 2012 in Barcelona was an overwhelming success. In the subsequent years, this annual scientific platform continued to grow and soon approximately 200 participants from over 40 countries were discussing all aspects of optimizing surgical care for IBD patients. Such aspects included pre-operative patient optimisation and technical aspects of various procedures to the influence of biological therapy on postoperative outcomes and the possibility to reduce recurrences by surgical techniques. This platform led to close friendships, fruitful collaborations, and new research initiatives. But



ECCO'16 Amsterdam 5th S-ECCO IBD Masterclass

it was more than that. For a long time, patients with IBD were operated on by gastrointestinal or colorectal surgeons with an interest in IBD, if they were lucky. Inspired by ECCO and S-ECCO, the concept of an IBD surgeon began to take shape. Over the years, management of patients with IBD has become increasingly complex while also becoming increasingly exciting. Although 'multidisciplinary treatment' has always been a popular term, involving a surgeon in daily practice was frequently limited to treatment-refractory patients. Denouncing this inconsistency from the perspective of multidisciplinary treatment has always been one of the main goals of S-ECCO. In fact, involving surgical expertise at an early stage of the disease is currently generally considered as good clinical practice; this can easily be considered as the biggest win.

Achievements of S-ECCO

Apart from the masterclass during the ECCO Congress, S-ECCO organises an annual symposium at the European Society of

Coloproctology (ESCP) conference and contributes to the scientific programme at the European Colorectal Congress in St. Gallen. To increase knowledge of the (im)possibilities of surgical options in the gastrointestinal community and to improve quality-of-care for IBD patients, S-ECCO promotes education by contributing to the ECCO Postgraduate Course in IBD and contributes to other educational activities organised by EduCom. S-ECCO spearheaded the globalisation of the European society by organizing educational meetings in Russia, Mexico, Colombia, Brazil, and the USA, thus connecting European and international IBD surgeons. This has resulted in a large presence in particular of Brazilian IBD surgeons at the annual ECCO meeting.

S-ECCO is also involved in the coordination of the surgical-treatment sections of various ECCO guidelines on Crohn's Disease and Ulcerative Colitis. There even is a specific surgical guideline on standards for timing and methodology of surgery in Crohn's Disease, which was created



ECCO'18 Vienna: 7th S-ECCO IBD Masterclass



ECCO'19 Copenhagen: 8th S-ECCO IBD Masterclass

in collaboration with the ESCP. Important publications include manuscripts addressing challenging situations, where a multidisciplinary approach is of crucial importance. This was accomplished by contributing to topical reviews, position statements, and scientific workshop papers. One example is the scientific workshop article addressing the pathophysiology and clinical impact of perianal fistulas in Crohn's disease (JCC 2016). The discussion on a reliable classification and the definition of proper trial endpoints improves the treatment of these patients by standardizing diagnosis and follow up, and, perhaps most importantly, by facilitating execution of well-designed trials.

Where we are going

One area that currently has our full attention is the discussion on 'high performance' in IBD surgery. Thus far, this has been a largely

ignored area. The lack of an evidence base, minimal political will, and absent measurement tools have all hampered the quality agenda; we must admit that other surgical disciplines, such as oncological surgery, are further ahead. Our first challenge in IBD surgery is to clearly define what is high performance or high quality. After all, we cannot improve what we cannot measure. The discussion about volume-related outcomes should follow. Efforts have been made in recent years to define benchmarks and create databases to monitor results at a national and international level. Such datasets could enable quality appraisal and lessons can be learned regarding the prerequisites to improve care. Various initiatives are being employed. The MIRACLE project, an international **M**ulti-**I**nterventional program to **R**educe chronic ileo**A**nal pou**C**h **L**eaks in UC, based on the UR-CARE database,



ECCO'19 Copenhagen: 8th S-ECCO IBD Masterclass

is a great example of how we aim to achieve high performance in IBD surgery.

The S-ECCO story: closing remarks

On a memorable evening in February 2018 at the general assembly in Vienna, Willem Bemelman, the former S-ECCO Chair, entered the ECCO Governing Board as Secretary with support of European and Brazilian IBD surgeons. Many gastroenterologists voted for a surgeon in the Governing Board, realizing that it was time to grant a surgeon an important position in ECCO. It also created some commotion. For a minute there were some mixed emotions; 'Would it be possible that a surgeon was going to lead ECCO'? But above all, there was excitement; this was the beginning of a truly multidisciplinary organisation.

T.S. Eliot wrote 'It is the journey, not the destination that matters'. But if you were to ask for my opinion on what is most important, I would say it is the company!

The S-ECCO adventure has been a fantastic journey, but this journey could only be so successful because of the friends we made along the way. It is now 10 years later. Time flies when you are having fun. But it feels like we have just begun. There are so many new initiatives and so many adventures to look forward to. Obviously, we had hoped that we could celebrate our tenth anniversary of S-ECCO with all of you, drinking a beer and having a dance. The COVID-19 pandemic threw a spanner in the works, but we are convinced that next year we will celebrate our second decade even bigger and better. The past 10 years have created a strong and close S-ECCO family, and we will easily pick up where we left off. The S-ECCO Committee would like to thank everyone who contributed to the S-ECCO story.

Christianne Buskens

on behalf of all (previous) S-ECCO Committee Members

Y-ECCO

Overall evolution since the launch of the committee

The Young ECCO [Y-ECCO] Committee started as merely an idea of a network for young physicians to keep contact after attending the ECCO IBD Intensive Course for Trainees. However, this idea quickly grew and developed from only being a means of networking with peers across Europe into an independent young investigator group led by a small group of dedicated young physicians, which could also foster research collaborations and introduce the next generation of researchers and physicians to ECCO activities. In 2006, Y-ECCO was officially founded during the ECCO General Assembly, with Gionata Fiorino elected as the first chair and Marc Ferrante as the first ECCO Secretary. However, it was only in 2007 that Y-ECCO was included as an independent committee in the ECCO Statutes as a group for ECCO Members not older than 35 or still in training. Y-ECCO was to operate under the supervision of SciCom and

EduCom to align its activities with those of the other ECCO Committees. Finally, in 2010 Y-ECCO came of age as the Y-ECCO Chair was included in the ECCO Operational Board.

Since these early days, much has happened with Y-ECCO and with the activities that Y-ECCO organises. While the committee over the years has become a regular part of ECCO, most of the original thoughts on the mission of Y-ECCO remain the same:

- Maintain friendship and collaboration between young clinicians and scientists
- Encourage scientific and clinical development to support continuing involvement in ECCO activities
- Participate in educational and scientific activities
- Act as a platform for all young clinicians and scientists



ECCO'13 Vienna: 6th Y-ECCO Workshop

Over time, Y-ECCO has slowly permeated all corners of ECCO. For many years, Y-ECCO has organised a workshop at the ECCO Congresses for young basic researchers. Previously, a career workshop was also organised; this has since evolved into the mentorship forum, which is a separate event for Y-ECCO Members independent from the congress. Y-ECCO has also become an important regular part of ECCO News and has featured interviews with esteemed ECCO Members and literature

within ECCO. This includes acting as a platform for young ECCO Members during congresses, where Y-ECCO Members chair plenary sessions, assisting with the Guided Poster Tour together with senior faculty, and ensuring that all ECCO publications have Y-ECCO participants in the working groups. Therefore, we have given young ECCO Members the opportunity to be active players within the organisation, to gain important experience, and to expand their network.



ECCO'15 Barcelona: 8th Y-ECCO Career Workshop

reviews. Seats for Y-ECCO Members are reserved for all ECCO Guidelines or Topical Reviews. But most importantly, many members of the Y-ECCO Committee continue to be active in the organisation and ECCO Presidents have previously been part of the Y-ECCO Committee. This emphasises the importance of Y-ECCO as a nursery for the next generation of ECCO.

What has been the main and most impactful activity?

Y-ECCO has made its impact on several places

A key activity for Y-ECCO has always been the workshops that take place during the ECCO Congress. These workshops initially began as a young investigator meeting and then split into a basic science workshop [addressing topics such as study methodology and design] and a career workshop [providing general career advice]. Recently, the career workshop has been separated from the congress as a one-day standalone meeting, the Y-ECCO Mentorship Forum, where participants have the opportunity to meet senior experts from the



ECCO'18 Vienna: 4th Y-ECCO Basic Science Workshop

ECCO Faculty and receive advice and scientific knowledge to the benefit of their careers.

hope that ECCO in the future will also facilitate visiting fellowships for young clinicians and researchers.

The Future of Y-ECCO

Y-ECCO Members are the future of ECCO and therefore the relevance and importance of this committee will surely remain high. Developing and mentoring the next generation of faculty members and officers is fundamental for the continuous evolution of ECCO. This highlights the importance of Y-ECCO activities as they offer a platform for young physicians and researchers to get involved in the organisation. In the coming years, we hope to expand our educational activities in terms of career guidance and take existing activities [such as the literature reviews] into the digital age with podcasts and vlogs. Ultimately, we

Johan Burisch



ECCO'17 Barcelona: 3th Y-ECCO Basic Science Workshop

JCC

Evolution of JCC in the past 10 years



ECCO'13 Vienna: Editorial Board Meeting

Since its inception in 2007, the Journal of Crohn's and Colitis (JCC) has been an integral part of the European Crohn's and Colitis Organisation (ECCO) and has played an increasing role in disseminating knowledge

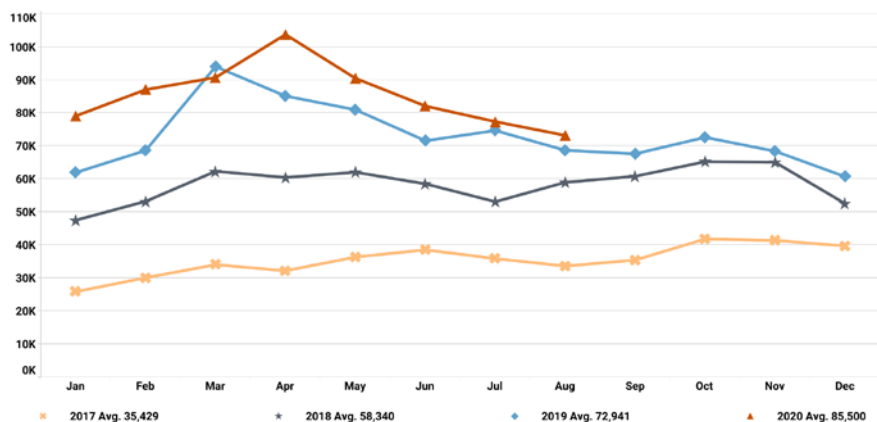
on clinical and basic science and innovative methods related to IBD. JCC is published monthly and features Original and Review articles, Editorials, Viewpoints, Letters to the Editor, and ECCO Congress abstracts, which are compiled and published as a supplement annually. Additionally, the journal publishes original manuscripts developed under the auspices of ECCO. These are ECCO Guidelines, ECCO Topical Reviews, ECCO Position Statements, and ECCO Scientific Workshop Papers (every 2 years).

Throughout the years, JCC has witnessed immense growth in terms of submissions, citations, and manuscript views, all resulting in a steadily increasing journal impact factor (compiled by Clarivate, 9.071 in 2020). The

Visits with Content Engagement over Time

How many visits have there been to the journal that included full-text (HTML+PDF) views and how has this changed over time? Monthly mean provided in legend

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impact factor is a measure of the frequency of which a typical article in a journal is cited in a particular year. It is used to measure the importance or rank of a journal by calculating the times its articles are cited.

The growth of the journal is due in part to the ever-increasing number of excellent manuscripts that are submitted. For 2020, we projected a total of approximately 1400 manuscripts submitted to JCC, which is an increase of approximately 40 % over 2019 figures. We published more than 200 articles in a year for the first time in 2020. This workload is managed with the involvement, dedication, and commitment of the editorial team. The number of Associate Editors has doubled compared to a decade ago (there are now 12 Associate Editors). This has resulted in increased efficiency, allowing for more manuscripts to be peer-reviewed and screened, thus ensuring that only the top-notch manuscripts are selected for publication.



ECCO'14 Copenhagen: Acknowledgement of Miguel Gassull

This has added considerably to the increased citation of and overall importance of the journal.

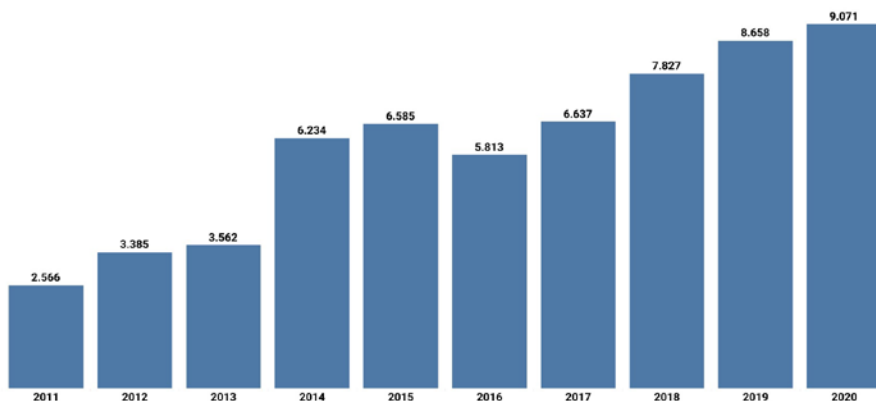
The Editor-in-Chief at the inception of JCC, who now carries the honorary title of Editor Emeritus, is Miquel A. Gassull. Dr Gassull passed the baton to me in 2014. Below is an illustration of the JCC impact factor between the years 2010 and 2019 provided by Oxford University Press, the publisher of JCC.

Impact Factor Trend

How has the Impact Factor changed in the last 10 years?

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ECCO'19 Copenhagen: Editorial Board Meeting

In addition to the impact factor, there are other ways to measure the impact of JCC in our community. Perhaps the most important of these is the number of downloads. For 2020, the readers of JCC downloaded full-text articles an average of over 85,000 times per month, which represents a growth of 15 % over 2019 figures. Many of the most downloaded articles are ECCO Guidelines, reflecting the fact that clinicians throughout the world use these publications on a daily basis to inform management of their IBD patients.

Finally, at JCC we endeavour to push the boundaries with the most up-to-date and authoritative information on IBD. In 2020 we published two supplements, the first on JAK inhibitors for IBD and the second on COVID-19 and IBD.

Thank you all for your ongoing support of the journal as readers, authors, and reviewers!

Laurence Egan

Editor-in-chief, Journal of Crohn's and Colitis



ECCO'19 Copenhagen: Editorial Board Meeting

UR-CARE

The duckling transforming into a beautiful swan

About 7 to 8 years ago during one of the many meetings at the ECCO Congress or UEG Week, probably in Barcelona, I found myself in a meeting with more than 20 people [what a strange and dangerous idea after 1 year of COVID] discussing the foundation of a pan-European IBD medical record. The architect of this very ambitious idea was Julián Panés, who, if I am not mistaken, had just joined the ECCO Governing Board.

I must admit that my initial thoughts were rather sceptical. I thought that this would never work and that it was probably wiser to withdraw myself from these meetings. But as I kept on being invited and moved up to the centre of the table, I gradually discovered that there was a lot of determination to succeed. There was a very active cooperation from the ECCO Office and full support from the Governing Board. I discovered that ECCO was a professional and well-run organisation and was powerful and ambitious enough to make it a success. Moreover, it had a research unit, IBD in Motion [IBDIM], which provided the ideal framework for the setup and development of this project.

Julián Panés experienced first-hand that ENEIDA, the registry from the Spanish IBD Group [GETECCU], had gradually evolved from the plan of a few large centres to a nationwide success. He convinced the Governing Board, the ECCO Office, and us from the working group of the enormous opportunities if we could bring this to a European and even global level.

With the invaluable support from the office, the first UR-CARE Taskforce started to build a registry with three European databases (ENEIDA, the Swiss IBD cohort, and Danish

registry) as major examples. We carefully selected all relevant variables, made them numeric, selected drop down options to allow for retrospective analysis, always carefully weighing completeness versus user friendliness. We performed multiple runs, made corrections, checked for inconsistencies, and learned a lot from the ENEIDA experience. In the next step, an IT partner was selected using an open call. We chose a Spanish company with a relevant track record of long-standing experience with large databases. This company has proven to be a very solid and reliable partner. The UR-CARE Steering Committee was soon founded and included Britta Siegmund [Berlin, SciCom], Javier Gisbert [Madrid, ClinCom, co-founder and active user of ENEIDA], Ebbe Langholz [Copenhagen EpiCom], and Filip Baert [Belgium, also from ClinCom and later ECCO Scientific Officer].

Our team has proven to be very active. As we gathered, the more the idea became a plan and our belief grew that UR-CARE was going to be a success. We interacted with ClinCom and also with P-ECCO and S-ECCO to include additional variables relevant for children and surgeons. The UR-CARE [United Registries for Clinical Assessment and REsearch] database itself was built. With the help of Y-ECCO observers, UR-CARE was validated for inter and intra-variability and a first paper was published in the Journal of Crohn's and Colitis in 2018.

Even with the construction of the actual database the work was not at all finished. Setting up the entire legal framework and contracts was the next task. As many parties



UR-CARE Steering Committee

were involved [patients, centres, study groups, IBDIM, and Persei], this turned out to be a major challenge. Nevertheless, we succeeded in developing a final template for a legal agreement to cover the use of UR-CARE for retrospective studies and for daily clinical care. From the data-protection side, the entire setup was cutting-edge legal technology. Even though this was all very new, the ECCO Office was always very supportive despite many challenges. Legal consultation was used at every step and a lot of time and meetings were required to set up communication and dissemination strategies.

After the launch in 2017, a contract research organisation was hired to build the prospective research module. With the help of Yamile Zabana and Manuel Barreiro Acosta [GETECCU], a first major achievement was to negotiate a Phase 4 study [PASS study] with tofacitinib and control arms. A study imposed by regulatory affairs with a large American company proved to be a bumpy marathon of meetings and

incremental numerous small steps before reaching the finish. Meanwhile, other academic studies were starting to use UR-CARE and a safety registry for pouch surgery.

Together with multiple aims, different levels of use were constructed [local in a centre, national or within study groups, and pan-European]. We negotiated with interested countries and existing study groups. Moving existing databases proved to be a bridge too far for now, as for the drivers or founders of these often-older registries it felt like giving away their baby. The first national database that is now synchronised with UR-CARE is the ENEIDA database, thus meaning that over 60,000 patients have been uploaded at once.

Despite scepticism from some, we believe that the way forward is join forces. The ECCO Spirit is not about competition but fostering collaboration on a voluntary basis, enabling all of us to collect real-world data in a structured and uniform way. UR-CARE is legally sound and GDPR-proof and uses a solid IT system that complies with all ISO certifications and safety checks.



ECCO'19 Copenhagen: UR-CARE Training Centre

Admittedly, identifying obstacles, conservatism, and protectionism is human and logical but not future proof. We believe that the future for UR-CARE is bright. We see the increasing relevance of collecting real-life data in many areas in medicine. Real-world evidence is of paramount importance for regulators, payers, and pharma companies, and therefore patients. Randomised controlled trials are no longer the holy grail to address all scientific questions. Larger cohorts are invaluable to compare therapeutic strategies and safety. Longer-term studies are needed to study the natural history of IBD and to prove current concepts, such as deep remission. Whether it is performing a small survey or search in your own patient pool, performing national studies and projects, or joining large pan-European or even global studies, UR-CARE will help the IBD field realise important projects and produce many publications.

All of this would not have been possible without the help of many people in the ECCO Office and past and current ECCO Presidents and Governing Board Members. At the risk of forgetting many people, a special thanks go to the entire ECCO Office team, Gerhard Rogler as

special deputy from the Governing Board, and of course my friends from the early days, Britta, Ebbe, and Javier.

Over the last year we saw a gradual but steady pick-up despite COVID-19. Contract approvals take time but have never failed. Even overseas in the US, UR-CARE documents are accepted.

UR-CARE is there for every single IBD doctor and is currently free to use. Please visit the ECCO Website for more information and e-mail us at contact@ur-care.eu on how to get started.

Centres from over 20 countries on four continents are currently using UR-CARE. Some countries are building a nationwide registry in UR-CARE. ECCO is setting up quality-of-care programmes using UR-CARE and core outcome data sets for real-world studies are being constructed in the registry. Many more initiatives and studies will take place using UR-CARE.

The proof of the pudding is in the eating. Major achievements take time; the composition of a symphony starts with one note. I believe we have only finished the overture. It is now up to all of you to fill out the rest.

So, sign up, join us in this big endeavour and help shape further how the registry can evolve!

Filip Baert

for IBDIM, also on behalf of the UR-CARE Steering Committee Javier Gisbert, Ebbe Langholz [Head], and Britta Siegmund

With grateful acknowledgement to the first UR-CARE Taskforce Members [Axel Dignass, Dana Duricova, Edouard Louis, Herbert Tilg, Julián Panés, Pierre Michetti, Tine Jess]

Why iron matters for patients with IBD

Iron deficiency anaemia (IDA) is the most common extraintestinal complication of inflammatory bowel disease (IBD), and negatively impacts many aspects of patients' quality of life.^{1,2} Norgine has worked with patients to understand their needs and to communicate the importance of iron to people diagnosed with IBD:

www.ironmatters.eu



Patients can learn about how IDA can affect them and what to do if they recognise symptoms, supporting each patient to quickly get the right iron treatment for them.

**Do your IBD patients
understand why
iron matters?**

References: 1. Stein J, *et al.* *Nat Rev Gastroenterol Hepatol* 2010;7(11):599–610. 2. Strauss WE, *et al.* *JCSO* 2016;14(8):342–350.

NORGINE and the sail logo are registered trademarks of the Norgine group of companies.
GL-HAE-FER-2100005. Date of preparation: August 2021.



Because patients inspire us

Country Members – Last 10 years

Country representatives

ESTONIA

The Estonian Society of Gastroenterology joined ECCO in 2014. As a small northern European country of only 1.3 million people, we do not yet have a separate IBD society. However, we believe that we have benefitted from joining ECCO in several ways. For example, we hosted an ECCO Workshop in Tallinn in 2015, which attracted the interest of Estonian gastroenterologists but also some surgeons as well. Our young gastroenterologists-in-training have benefitted from participating in the IBD Intensive Course for Trainees, which they have rated highly. Furthermore, our IBD Nurses have benefitted

from N-ECCO courses and an ECCO Travel Award enabled a young gastroenterologist to visit a renowned IBD centre in Cambridge, UK.

We appreciate the high-quality guidelines that ECCO publishes and we regularly use them in our everyday clinical practice. Our patients have found the translated ECCO-EFCCA patient guidelines to be helpful.

We have enjoyed participating in the ECCO Congress and value it for its high scientific level and friendly atmosphere. The networking events have been great for making new friends and meeting old ones in a relaxed atmosphere. We look forward to continuing cooperation with ECCO!

Hendrik Laja & Karin Kull



MALTA

In 2015, I was invited to the ECCO General Assembly and Malta was accepted as a full member of ECCO. Since then, we have always felt that we belong to a very supportive ECCO Family. Most, if not all, IBD patients in Malta are managed in our main National Health Service hospital. Joining ECCO has opened new horizons, and this has meant much more than just attending the yearly conference!

Our trainees were able to start attending the IBD Intensive Course for Trainees. I knew the value of this course (both in terms of educational content and networking), as I attended this course myself when I was a trainee. The trainees' feedback on this course has always been excellent. This led to further exposure of our trainees to the IBD scientific community, thus stimulating a more genuine interest in the subject and an eagerness to be involved in various research studies. The friendly nature and willingness to help everyone within ECCO definitely encouraged our young trainees to develop more than just an interest in IBD.

Their 'ECCO stories' led to further interest from those who had never been before. Over time, our nurses started attending the Nursing IBD courses and the conference as well. Dietitians then followed suit. Similarly, setting up of our IBD MDT led to histopathologists and surgeons attending the relevant ECCO courses.

Coupled to this was our involvement in various ECCO projects, such as the ECCO Guidelines, Topical Reviews, and CONFER Cases. We have met colleagues who have become very close friends, and this has resulted in collaborations in different multicentre studies. All of this has led to the development of an ever-growing group of interested and motivated healthcare professionals in IBD, which ultimately and more importantly leads to a better quality-of-care for our IBD patients.

Finally, I would like to thank everyone within ECCO for giving us this opportunity.

Pierre Ellul



ECCO going digital

ECCO's digital story started with one website, which evolved over time to eventually capture all information about ECCO Activities, from the Association to the Congress. As the world's

digitalisation accelerates (and continues to do so!), ECCO did not stay behind and turned the digital corner as well.

e ECCO Portal

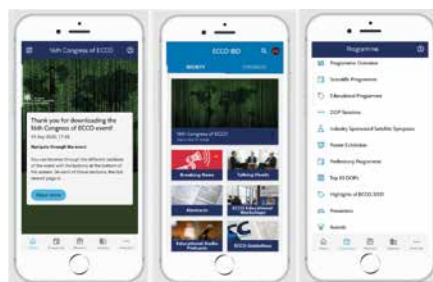
Along with a modernisation of the layout and content of its website, ECCO launched the ECCO Portal in 2018 to replace its Members' Restricted Area. With the ECCO Portal, ECCO Members have their account and membership information centralised, can apply for ECCO Activities [ECCO Fellowships and Grants and Travel Awards, ECCO Publications, ECCO Elections, among others], submit an abstract to the ECCO Congress, manage their Congress registration, and access the Journal of Crohn's and Colitis [JCC] for free* and the entire content of the e-CCO Learning platform. The ECCO Portal is the essential tool for all ECCO Members to actively participate in ECCO Initiatives.



*Regular and Y-ECCO Members only

The ECCO IBD App

ECCO launched its new ECCO IBD App in 2019. With this app, everyone has the world of ECCO in their pocket. This app allows users to follow ECCO's society news and projects and also improves the ECCO Congress delegate experience. It is free of charge and enables users to access all ECCO material to read, listen, or watch on the go [such as the ECCO Educational Audio podcasts, the Talking Heads videos, or the ECCO News Issues]. At the ECCO Congress, delegates can create their own daily schedule and take notes in the App during the sessions. They can access the event programme and the speakers list and browse through the list of



exhibitors and corporate members. Delegates can read the abstracts, watch the ECCO Film, and find all useful information for the congress days in one spot.

Digitalisation of the ECCO Congresses

Live transmissions

For the first time in 2020, ECCO Members could follow the live transmission of the Scientific Programme online via our Webcast Website or the ECCO IBD App. In addition, the Webcasts of the 10 digital oral presentation sessions have been made available on-demand.

These live transmissions and on-demand videos are a great expansion of the on-demand content of four selected educational courses that have been published each year since 2013.

Slide Review Stations

The Slide Review Stations in front of the Plenary Hall were introduced at the 2020 Vienna Congress. Delegates had the opportunity to review the slides of past presentations of ECCO'20 and catch up on missed content at their own pace.

e-Terminals at the ECCO Booth

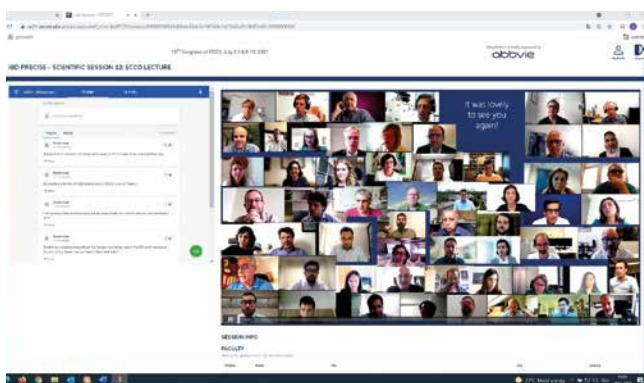
At the ECCO Booth, delegates can use the e-Terminal stations and openly access various ECCO Initiatives, such as the e-Library, the e-Guide, Skills Videos, Educational Audio Podcasts, JCC, and much more.

ECCO Industry Webshop

For the 2021 Congress, ECCO launched its Exhibitor & Sponsor Webshop to facilitate communication and exchange with Industry partners. Apart from receiving general information, interested companies can browse through sponsorship offers and secure their promotional and physical presence at the Congress. The ECCO Industry Webshop is not only valuable prior to the Congress, but also offers stakeholders opportunities year-round with the incorporated and digitalised Media Kit.

ECCO'21: 100% virtual

In February 2020, ECCO organised the last physical congress in Vienna before the COVID-19 pandemic forced the world to shut down. When it became clear that the ECCO'21 Congress could not be organised as a physical event, ECCO adapted and prepared a fully virtual congress for the first time in the history of the organisation, with many features to ensure a positive and interactive congress experience. The heart of ECCO'21 was the virtual congress platform, which was created to centralise the entire ECCO



Congress, such as its programmes, materials, and connection of delegates. All presentations were given live online by the speakers, and presentations were video-recorded and made available on-demand for all delegates to watch until end of October 2021. Other corners of the ECCO Congress were turned into virtual spaces. Industry had the opportunity to interact with the delegates at their virtual stands in the virtual exhibition, questions could be directed to the ECCO Office at the Virtual ECCO Booth, and the traditional hard-copy posters were displayed as e-Posters.

e-CCO Learning

The screenshot shows the ECCO e-CCO Learning platform homepage. At the top, there is a dark blue header with the ECCO logo (European Crohn's and Colitis Organisation) on the left, a search bar in the center, and the 'ECCO PORTAL' logo on the right. Below the header, a navigation menu includes links for 'About ECCO', 'Congresses & Events', 'Membership', 'Education', 'Science', and 'Publications'. The main content area is titled 'Welcome to e-CCO Learning'. It features three sections: 'ECCO Members Access' (stating full content is available to paid members via the ECCO Portal), 'e-Learning Subscribers Access' (introducing a free subscription for healthcare professionals), and 'e-Learning Visitors' (welcoming visitors and explaining how to access content). Below these are three more sections: 'LETTERS FROM THE E-LEARNING AMBASSADOR', 'E-COURSES' (describing a collection of case-based courses), and 'E-LIBRARY' (describing a host of abstracts, presentations, and other resources).

The e-CCO Learning platform is a multifaceted instrument designed to improve knowledge and enhance the educational experience in the field of IBD. It is structured around two main complementary pillars, the IBD Curriculum and the e-Library. The platform has been improved over recent years; the content has been refined and the layout modernised to improve the user experience, allowing for better visibility of the material. An improved search function has also been incorporated.

The IBD Curriculum is the backbone of the e-CCO Learning platform, as it outlines the basic understanding that gastroenterologists must have to be considered as experts in IBD. It comprises 16 categories. Each category has a mix of material [webcasts, slides, and tools collected during ECCO Congresses and beyond] that can assist gastroenterologists in improving their expertise in IBD in these particular topics. Furthermore, additional content and topics can be found in the e-Library, which contains

all the e-CCO Learning material, searchable by year, type of content, IBD Curriculum category, keywords, or via free text.

In addition to the Congress material, the e-CCO Learning platform encompasses various educational elements developed by and with the ECCO Officers. This includes the Educational Audio Podcasts, which address specific areas in the management of IBD patients; the Talking Heads videos, which capture discussions around controversial topics; the Skills Videos, which provide brief and practical tips and tricks; and the e-Courses, which comprise a case-based clinical narrative based on ECCO Guidelines and Topical Reviews. ECCO also regularly collaborates with partner organisations to develop new content, such as the Transatlantic Talking Heads where an ECCO and a Crohn's & Colitis Foundation speaker exchange views on a topic from a European and from a North American perspective.

Some of this content is only accessible to ECCO Members. However, since 2020 all healthcare professionals under 35 or still in training and with an interest in IBD can access the entire e-CCO Learning platform without an

active ECCO Membership. It is ECCO's goal to support the next generation of IBD healthcare professionals by giving them access to high-quality educational material.

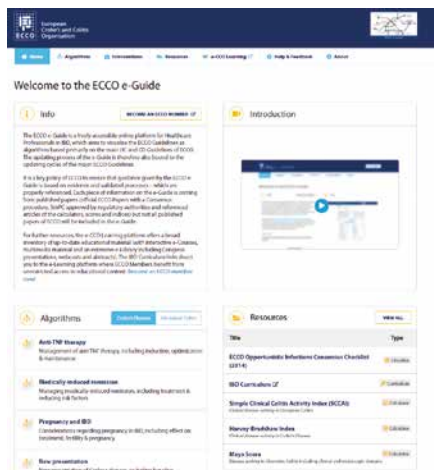
The e-Guide

The ECCO e-Guide is a practical tool that is freely accessible online to assist healthcare professionals in the management of their patients with IBD.

The main features of the e-Guide are the CD and the UC algorithms. Based on the ECCO Consensus Statements, the e-Guide shows the journey of an IBD patient; depending on the diagnosis and the situation, the e-Guide also shows the best steps in managing patients throughout this journey. The updating of the e-Guide is bound to the updating cycles of the major ECCO Guidelines and therefore occurs on a regular basis.

In 2019, thanks to an educational unrestricted grant from a corporate partner, the e-Guide was given a facelift. The layout was modernised and the content was reorganised. In the Interventions tab, the list of available therapeutic treatments was updated, also with information on how to use and monitor them based on the summary of product characteristics approved by regulatory authorities. A brand-new feature was introduced in the e-Guide's Resources; IBD calculators were included to calculate the most commonly used clinical and endoscopy scoring systems to assess not only disease activity but also patient-reported disease control. The e-Guide now encompasses the following 12 calculators:

- Simple Clinical Colitis Activity Index [SCCAI]
- Harvey-Bradshaw Index
- Mayo Score



- Ulcerative Colitis Endoscopic Index of Severity [UCEIS]
- Simple Endoscopic Score [SES-CD]
- Rutgeerts Score
- Lewis Score
- Paediatric Ulcerative Colitis Activity Index [PUCAI]
- Paediatric Crohn's Disease Activity Index [PCDAI]
- Weighted PCDAI [wPCDAI]
- Pouchitis Disease Activity Index [PDAI]
- IBD Control [without VAS]

Not only are these calculators integrated in the platform, they are also accompanied by an introductory video where an ECCO Officer explains the purpose of the score, how to use it, and its strengths and weaknesses.

ECCO News

10-year evolution

Dear ECCO friends and colleagues,

We hope you have been keeping safe and well.

We have all learned to come together and deal with the unprecedented circumstances that the year 2020 has thrust upon us. It has been a year of reflection and an opportunity to learn from the past and plan for the future. We are springing into action in 2021 and are looking forward to celebrating ECCO's 20th anniversary.

As a colorectal and IBD surgeon, being part of ECCO over the last 10 years has been an absolute honour. It has been a delight getting to know people from different parts of Europe and the world. My ECCO journey started with membership, abstract presentations, involvement in Y-ECCO Literature Reviews and other activities, becoming a Y-ECCO Committee Member, and subsequently becoming the first surgeon to chair the sub-committee. I was

delighted to become an associate editor for ECCO News in 2018, working alongside Willem Bemelman as the Editor and Ignacio-Catalan Serra as the co-Associate Editor.

As the society continued to grow, so have the collaborations and global and personal growth. What ECCO News stands for, and what this quarterly newsletter has done, is to bring our ECCO Community together in the truly friendly and collaborative spirit of the society.

You might have noticed some changes in ECCO News over the last 10 years. Initially, and prior to 2011, ECCO News was managed by an external publishing agency, Mediahuest. This might have been important initially to set up our community newsletter. However, in 2012, an executive decision was made to manage the newsletter internally by our amazing ECCO

ECCO News



2020/1



2020/2



2020/3



2020/4

ECCO News keeps ECCO Members up-to-date on what is going on within the organisation and reports on IBD activities taking place within Europe. Since Spring 2006, ECCO News has maintained the flow of information between Members of the organisation.

ECCO News is an important part of the European Crohn's and Colitis Organisation's ambition to create a European standard of IBD care and to promote knowledge and research in the field of IBD. ECCO Members automatically receive this publication four times a year.

SEARCH ECCO NEWS

- LETTER FROM THE ECCO PRESIDENT
- COMMITTEE NEWS
- CONGRESS NEWS
- LITERATURE REVIEWS
- UR-CARE
- EU PROJECTS
- COUNTRY MEMBER PROFILES
- FELLOWSHIPS & GRANTS REPORTS



Office Staff. This was a very important step for several reasons, including the fact that the ECCO Office was still doing most of the leg work and most royalties were channelled away from the society. Having ECCO News run by ECCO for ECCO meant that funds from ECCO sponsors did not go to external bodies. ECCO Officers were proud to contribute to the newsletters, which were available both as hard copies and online. The design changed to the current one you are still seeing today.

Sustainability is always at the forefront of any society and this was one of the reasons why ECCO News became an online-only publication in 2017. This was part of the vital transformation of our society in 2015, when the involvement of the GB was deemed important to improve all workflows, hence the online-only publication of ECCO News.

In the true collaborative nature and MDT style of ECCO, the new associate editors, appointed in 2018, have been working closely with the ECCO Office to revitalise ECCO News. We have

transformed ECCO News into a much more flexible online medium, where one has the original option of looking at the full newsletter in PDF or clicking on the online sections and reading specific sections or each in turn on a normal web browser. Having thoroughly enjoyed leading the Y-ECCO Interview Corner for several years, it was great to be able to continue and share that role as an associate editor, where the two associate editors have been alternating in the interviewer role and in the selection of the interviewees. Another great transformation was bringing technology into the heart of ECCO and recording the interviews for some easy listening.

The last 10 years have been phenomenal for ECCO and ECCO News. We are looking forward to continuing our collaborative work, highlighting previous achievements, and to growing from strength to strength over the next 10 years.

Nuha Yassin

On behalf of the ECCO News Editorial team

"3, 2, 1 - Action!"

ECCO Congresses put in motion since 2012

It all started in Barcelona with the first and hugely successful Public Awareness campaign ***Join the Fight against IBD 2012***, a joint effort of EFCCA, ECCO, and loyal industry partners. Patients, specialists, patient associations, scientific societies, and sponsors came together to build a giant bowel in the Olympic Stadium 'Lluís Companys' to show their commitment to the cause as a symbol of unity, teamwork, engagement, and victory. The Olympic spirit and the united effort were captured in a powerful video that was created by our film company partner.

Two more campaigns of ***Join the Fight against IBD*** followed: one in Vienna (2013) and one in

Copenhagen (2014), both supported by creative content. This was the point when it became clear that ECCO was not lacking in creativity, thus ECCO continued its collaboration with our film company partner to give the ECCO Congress an even more special touch with the ECCO Congress trailers.

With themes covering ***Touring De Force on IBD***, travelling with a time machine to advance knowledge and improve care and fighting IBD as secret agents or spies, ECCO was undoubtedly getting into action!

Whether ECCO's film stars were after recipes that would remove IBD from the table or after



ECCO'13 Vienna: Opening of the Scientific Programme



ECCO'15: With our film company on the set



ECCO'17 Barcelona: Film projection



ECCO'18 Vienna: Opening

a potion that would heal IBDx, ECCO's Congress films have carried on the so-called IBD 'brush' of hope to promote scientific excellence that comes together at the ECCO Congress from all over the world.

The congress films are shared with the ECCO Family in three forms: as a trailer and as an opening and closing film. These films try to present the ECCO Congress with a different, refreshing touch. The stories usually evolve from the ECCO Scientific Programme theme, trying to establish a connection with the congress destination. Humour is, of course, of paramount importance! Moreover, apart from their daily routines, the starring roles of the Organising Committee Members in ECCO films have often led to the discovery of new and unexpected talents.

Creativity also made its way to the congress openings, with a special welcome moment where all ECCO Officers come on stage,

wearing theme-related t-shirts and 'gadgets'. These theme-related giveaways have become especially popular and have brought the ECCO spirit to the homes of our international IBD community, even after the congress ends.

With ECCO Congress trailers and special congress openings, ECCO tries to give the congresses a human touch; it strives to connect in the spirit of friendship and family. ECCO believes that with the right spirit as an organisation, even larger challenges can be conquered together.

Needless to say, creativity and humour are ways to connect and find common ground for friendships and working partnerships. Coming together gives room to projects that advance research and science, and this is the most essential objective and our common goal: fighting IBD and improving patients' lives!

Anja Bunderla

ECCO Office Story



Opening of the ECCO Office

Along with the ECCO Family, ECCO's homebase – the ECCO Office – has been thriving over the past 10 years. The ECCO Family dynamic that we are all familiar with has been reflected in the ECCO Office team right from the start. In 2010, when ECCO made the decision to establish its own head office, Daan and Nicole built up the ECCO Office team, then consisting of four members, in the first year.

To bring ECCO News in house, to develop the ECCO e-Learning platform, to support an increasing number of ECCO publications, to reinforce the success of JCC, and to support the Join-the-fight awareness campaigns, the team grew gradually to 10 members in 2014. These were the days when the representative animals were chosen for and together with the ECCO Committees, which have ever since then allowed the endearing reference of the zoo of ECCO.

As more office space was needed, the Office moved to a larger rented place. Expansion was not only needed in terms of team members and physical space, but also on the structural side. As early as 2012, the congress business unit had to be transferred to a daughter company called OCEAiN, while the second daughter company, IBDIM, was founded in 2014 as research unit of ECCO. This was in parallel to gaining the first experience in participating in EU projects. In particular, the full name of OCEAiN has been a repeated challenge. For example, when it came to completing official forms, the 'C' for 'congress' and 'A' for 'association' simply did not do justice to the ECCO dynamic; the 'E' for emotion and the 'I' for 'innovation' had to be in the name as well.

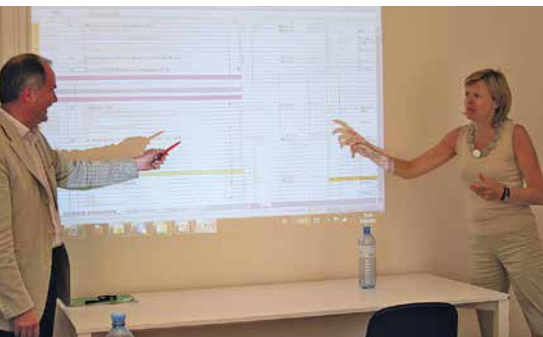
For ECCO'15, the congress registration was brought in-house to allow ECCO to benefit



ECCO Office under construction



Opening of the ECCO Office



Work in progress

from long-term cost efficiency and to turn the 'ECCO database' into the 'Ferrari' of data administration. This came just in time to accommodate the rapid growth of the ECCO Congress and the ECCO Family.

The team size increased to an average number of 17 members very quickly. Enthusiastic research discussions within the ECCO Committees triggered the start of the UR-CARE project within ECCO's research unit, while stronger bonds at the national level in all ECCO Member countries were further fostered via the stand-alone National Representatives Meetings. Not surprisingly, the ECCO Office again needed more space. After an intensive search effort over several months, the ECCO Office finally found its home in Ungargasse 6, 1030 Vienna. With a safeguarding investment plan, ECCO now bought its own office. After a thorough renovation, the ECCO Officers and the ECCO Office team celebrated the inauguration of the new home of the ECCO Office in the framework of the ECCO Summer Meetings 2015.

However, the preparations for ECCO'16 Amsterdam started to reveal the need for consolidation. The great success of ECCO, with its 'just do it' approach, had now reached a size that had to be based on more cautious and long-term planning to still allow ECCO to fit onto a shortlist of suitable congress centres within Europe and to avoid bottleneck situations at the project level. This has been a continuous effort over recent years. At the same time, ECCO continued to uphold its pioneer spirit with many exciting new projects and a strong focus on a multidisciplinary team. During this time, ECCO established its own IBD Nurse Education Programme. The courses for dietitians, histopathologists, and clinical trialists within the educational congress programme started to complement the successful courses already offered for gastroenterologists, surgeons, and nurses. On the scientific side, the diversity and funding volume of the ECCO Fellowships and Grants portfolio also experienced a boost. Many of these initiatives were supported



ECCO Office Team

by corporate partners, with whom our collaboration has also been strengthened in recent years.

ECCO developed its own IBD Curriculum, to which the e-Learning platform and the overall e-Library search mechanism have been aligned. Moreover, the e-Guide was also integrated and serves as an up-to-date bridge to the main ECCO Guidelines statements and recommendations displayed in algorithm flowcharts. The ECCO Guidelines themselves introduced GRADE methodology for its main treatment Guidelines and the new official ECCO manuscript category 'ECCO Topical Reviews' was rapidly developed with highly respected publications.

The digitalisation of the ECCO Congress was further developed successfully with each passing year. This included the introduction of the new ECCO App, which is not only focused on the congress days themselves but also aims to provide a useful tool throughout the year

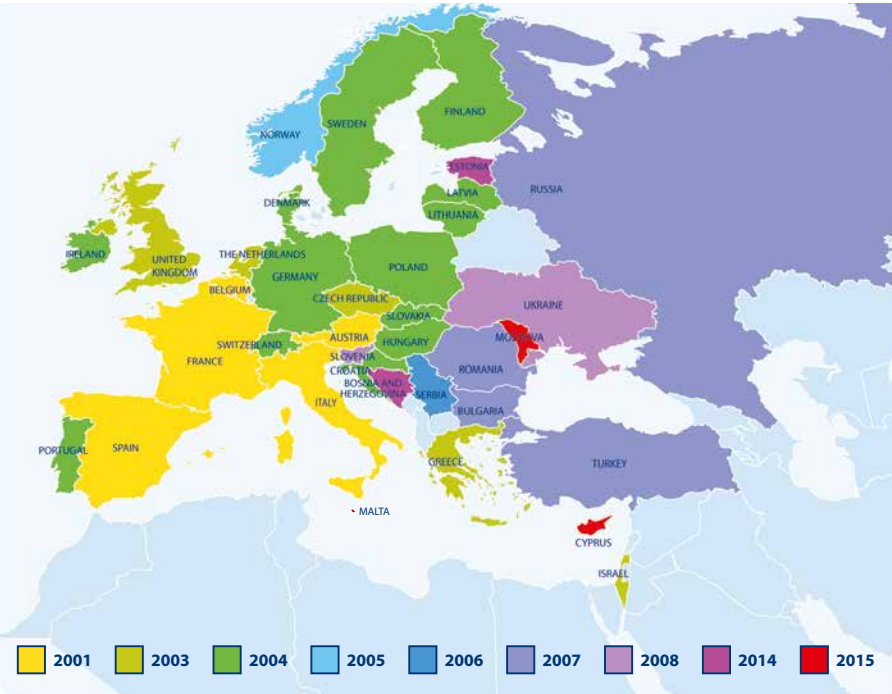
as a society app. Of course, the ECCO Website remains the primary window to the public world, and here the layout has also evolved over time while trying to maintain a functional and friendly format. The ECCO Portal is now the single entrance door for log-in activities.

It was the teamwork of the ECCO Officers together with the ECCO Office team that made implementation of these projects a success. In turn, the ECCO Office relies on the services of third-party suppliers; several of them have also accompanied the ECCO Family for many years and have truly become partner companies.

As for the past, present, and future, we would like to thank the ECCO Office Team members for sharing the ECCO spirit and making a personal contribution to our daily work to uphold this spirit with great commitment and flexibility.

Nicole Eichinger & Julia Gabriel

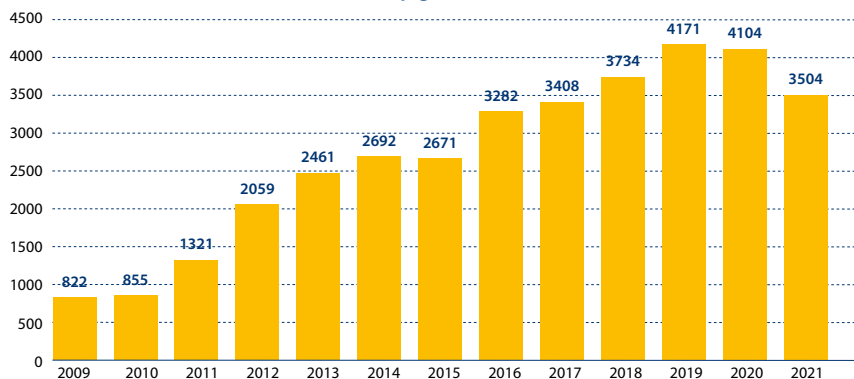
List of Member Countries



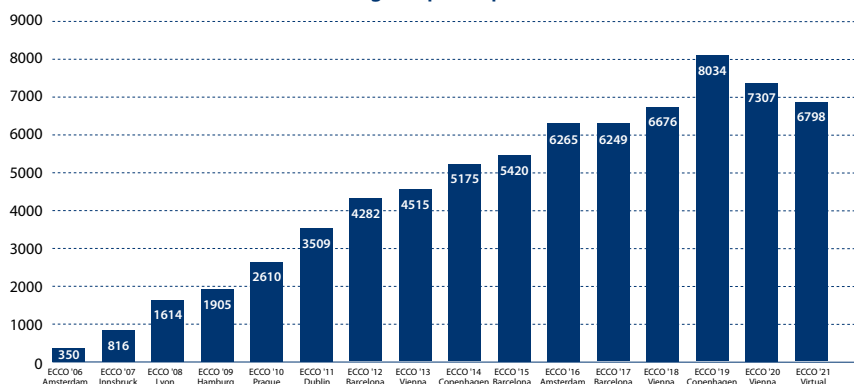
ECCO's growth in country membership

Austria	Greece	Portugal
Belgium	Hungary	Romania
Bosnia and Herzegovina	Ireland	Russia
Bulgaria	Israel	Serbia
Croatia	Italy	Slovakia
Cyprus	Latvia	Slovenia
Czechia	Lithuania	Spain
Denmark	Malta	Sweden
Estonia	Moldova	Switzerland
Finland	Netherlands	Turkey
France	Norway	Ukraine
Germany	Poland	United Kingdom

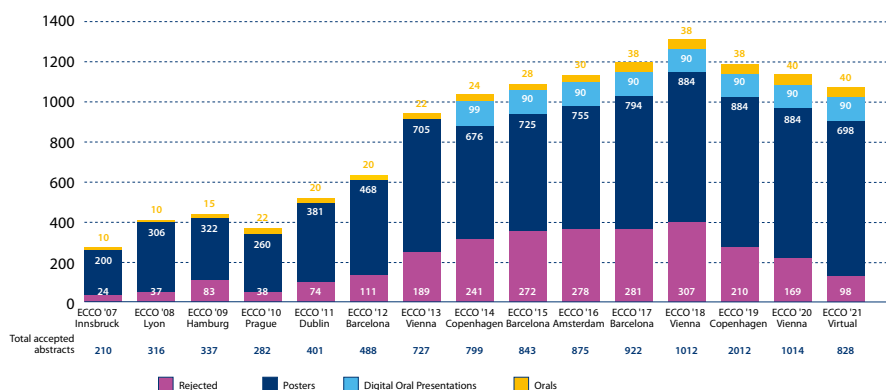
ECCO Membership growth 2009-2021



ECCO Congress participation



Accepted vs. rejected abstracts



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Baert Filip
Bemelman Willem
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 van der Woude Janneke
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Panis Yves
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 Lee James
 Nunes Tiago
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Raine Timothy
 Rieder Florian
 Samaan Mark
 Scaldaferri Franco
 Sheng Ding Nik
 Verstockt Bram
 Wehkamp Jan
 Yassin Nuha
 Zeissig Sebastian

Picture gallery



ECCO'12 Barcelona



ECCO'12 Barcelona



ECCO'12 Barcelona



ECCO'13 Vienna



ECCO'13 Vienna



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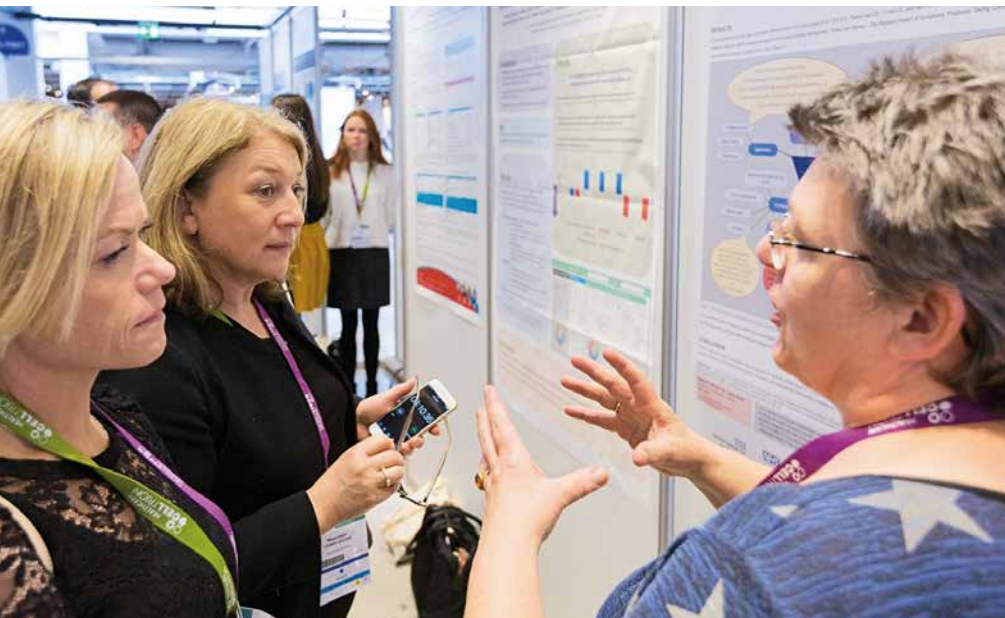
ECCO'18 Vienna



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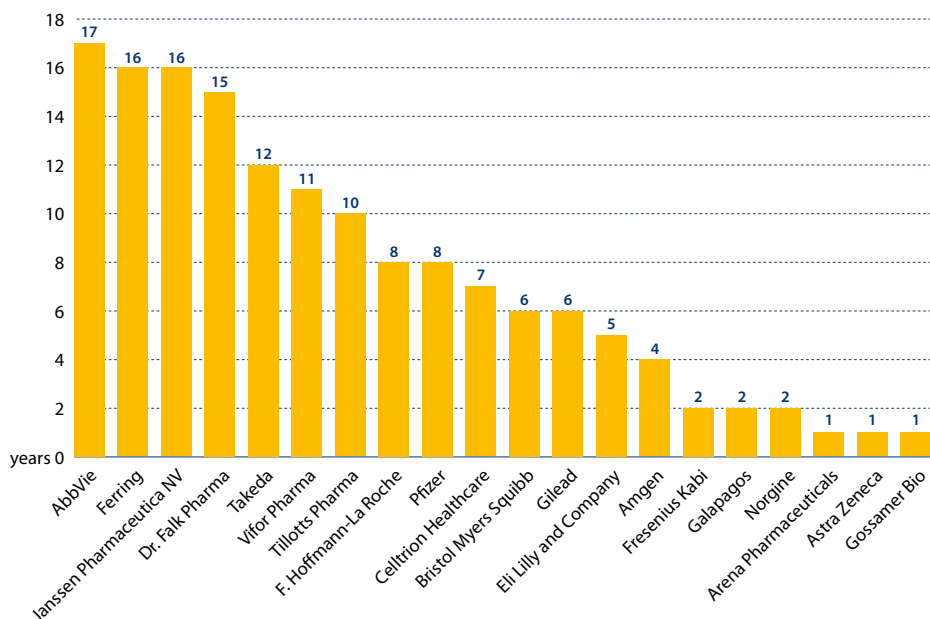
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