



**Report**

**INTERNATIONAL  
SYMPOSIUM  
ON RESEARCH  
SUPPORTED  
BY PATIENTS'  
ORGANISATIONS**

**BUCHAREST 27 MAY 2018**



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



## CONTENTS

- 3 Setting the scene
- 4 The Symposium
- 7 Methodology
- 11 Next steps
- 12 Take home message
- 13 Annex 1: list of research projects presented at the Symposium
- 11 Annex 2: short biographies of the moderators

European Federation of Crohn's and Ulcerative Colitis Associations

Rue Des Chartreux, 33-35  
Brussels B 1000 - Belgium

Phone: +32 2 540 84 34  
Fax: +32 2 540 84 34

[www.efcca.org](http://www.efcca.org)

## SETTING THE SCENE



**United We Stand**

In October 2012, over sixty IBD (Inflammatory Bowel Disease) patient associations from all over the world met in Brussels for the first ever Symposium on IBD research funded or promoted by IBD patient associations, organized by EFCCA (European Federation of Crohn's and Ulcerative Colitis Associations).

The Symposium gathered evidence and information from patient associations that directly fund or promote research into the causes and treatment of IBD and provided a unique platform for IBD associations from around the world to exchange ideas in developing strategies for supporting research.

A strong presence of internationally renowned gastroenterologists and other health care professionals contributed in the success of the event, and afterwards, a White Book on IBD Research was published by EFCCA. The White Book emphasized the importance of patient organizations partnering with scientific societies and physicians' organizations also taking a more active role in bringing patients and physicians together.

A lot has happened since the symposium in 2012. EFCCA has grown not only in numbers, but geographically as well; the federation is attracting interest worldwide, and IBD patient associations also from outside of Europe have joined.

Projects have been carried out within EFCCA in collaboration with other patient and doctor organizations, industries and universities. EFCCA has also carried out its own projects: for example, EFCCA has performed a large patient survey "BAB – Biologics and Biosimilars" to assess patients' knowledge and concerns about biosimilars and a project mapping access to and availability of new innovative medicines in the member countries.

The World IBD Day, initiated by EFCCA, has grown into a worldwide campaign raising awareness about IBD.

### **WHY THE NEED FOR A SYMPOSIUM ON IBD RESEARCH FUNDED OR PROMOTED BY PATIENT ASSOCIATIONS?**

EFCCA believes that patient associations' involvement and a more active role in IBD research is essential if we want to see any significant change in the quality of life for people with IBD.

Therefore the second Symposium on IBD research organised by EFCCA on 27 May 2018 in Bucharest aimed to reinforce the patients' role and voice in research to address the real needs and priorities of the patient community. The Symposium aimed to strengthen relationships and know-how within the IBD community and to support a more robust exchange of information worldwide. At the same time, the Symposium offered the IBD patient associations and the scientific community the chance to discuss and lay the grounds for an information model that lets each patient association, individual and researcher know what topics are being investigated, to evaluate or develop co-operations and common projects, to create synergies and to better develop research strategies.



# The Symposium

The second Symposium, held at the Hilton Garden Inn in the old city of Bucharest, Romania, on Sunday, 27 May 2018, brought together over 80 representatives from patient groups from five continents, gastroenterologists, other healthcare providers and relevant stakeholders.

After the opening by (now former) EFCCA Chairman Martin Kojinkov, Professor Mircea Diculescu, a founder member of Romanian Crohn's and Colitis Club and member of ECCO's strategic board, welcomed the audience to Bucharest. He emphasized the important role of well working teams in medicines and recognizing that the patient is an equal partner of the team together with the doctor, and as such, "we have to understand each other, understand the needs and demands, share experiences and empower the patients with the decisions of what will be done for the disease".

## THE SYMPOSIUM

A compelling keynote speech was given by Professor Claudio Fiocchi from the Cleveland Clinic Foundation – Lerner Research Institute. He also emphasized the importance of patient participation in IBD research as they bring a different perspective and see things that the medical community doesn't. Professor Fiocchi had a clear message to IBD patients: "Strength is in numbers. Wisdom and knowledge are in numbers. We need little bit of luck too, but strength is important and you are the strength." The floor was then given to patient associations, which had the opportunity to present their research projects for the audience. Altogether twelve EFCCA member associations presented their research. A full list of the presenters can be found in Annex 1.



Patients bring a whole different perspective; they see things that we don't. Strength is in numbers. Wisdom and knowledge are in numbers. We need a little bit of luck too, but strength is important, and you are the strength.

*Professor Claudio Fiocchi*



Professor Claudio Fiocchi giving his keynote speech

## THE SYMPOSIUM

“

As a team, the doctor and patient have to understand each other, understand the needs and demands, share experiences and empower the patients with the decisions of what will be done for the disease.

*Professor Mircea Diculescu*

”



Professor Mircea Diculescu giving his welcome speech

## Methodology

The patient associations' presentations were divided into three clusters. Each of them focused on a specific topic chosen according to the outcomes of consultations among EFCCA members and prominent international medical societies.

Each cluster was moderated by internationally renowned experts and included also time for discussion and questions from the audience, which complemented the sessions.

For the short biographies of the moderators, please see Annex 2.

## METHODOLOGY



Alexandra Giliati presenting a research project from Greece

### PATIENTS' PRIORITIES AND UNMET NEEDS IN RESEARCH

Cluster 2, "Patients' priorities and unmet needs in research" was moderated by Professor Adrian Saftoiu (University of Medicine and Pharmacy, Craiova, Romania), a member of the United European Gastroenterology (UEG) Public Affairs Committee.

The research priorities of people living with IBD on a day-to-day basis may not be the same as those of physicians and scientists; the issues faced by patients in their daily life may not always be those prioritized in research and its funding. The scientific community has to understand also the needs of the patient community. The presentations in Cluster 2 touched on topics that may be important for IBD patients and patient associations but are not necessarily always found in the front line of scientific research, e.g. post-traumatic stress, IBD epidemiology, patient education program efficacy and dietary factors. For more information on the presentations, please see Annex 1.

### NEW CHALLENGES BEYOND ORIGINATORS AND BIOSIMILARS

Cluster 1, "New challenges beyond originators and biosimilars" was moderated by Professor Ron Shaoul (Pediatric Gastroenterology Institute, Ruth Children's Hospital, Rambam Medical Center), who represented the European Society for Paediatric Gastroenterology Hepatology and Nutrition (ESPGHAN).

Biologics and biosimilars has been a hot topic within the IBD community for several years already, and as more such medications enter the market and more IBD patients are treated with them, they raise new questions in terms of e.g. costs, patients' quality of life and vaccinations for persons treated with immunomodulators; these topics were presented and discussed in Cluster 1.

For more information on the presentations, please see Annex 1.



Adam Elgressy presenting research carried out in Israel

## METHODOLOGY

### PATIENT-CENTERED RESEARCH AND CLINICAL TRIALS: WHAT DO PATIENTS NEED?

Cluster 3, "Patient-centered research and clinical trials: what do patients need?" was moderated by Professor Gerhard Rogler (Zurich University Hospital, Switzerland); Scientific Officer of the European Crohn's and Colitis Organisation (ECCO) Governing Board.

The patient needs to be at the focus of research, and research needs to be relevant to the patient. To make sure the patients and their needs are not overlooked, they should be involved in the design and implementation of research projects.

Cluster 3 aimed to give an idea of what patients might need in terms of research and how patient associations can get involved in different research projects, and presentations touched on topics such as the impact of IBD on quality of life and employment, hospital audits and self-managing symptoms via an online program. For more information on the presentations, please see Annex 1.



Wayne Massuger presenting research done by the Australian association



## METHODOLOGY

The Symposium finished with an inspirational presentation on new research by Dr. Joana Torres from the Gastroenterology Department at Hospital Beatriz Ângelo in Loures, Portugal.

She spoke about paving the way for future scenarios by explaining ideas of prediction and prevention of IBD, IBD in early life, and finally, presenting a survey on the phenotypic features of IBD in couples with IBD and their offspring.

She stressed the importance of striving to understand the pre-clinical stages of IBD, as this might help in predicting and preventing disease development, and studying risk populations to improve the knowledge of IBD pathogenesis, development of new therapeutic targets, and eventually preventive strategies.

“

“Understanding the pre-clinical stages of IBD might enable accurate identification of at-risk individuals for disease development.”

*Dr. Joana Torres*



Dr. Joana Torres from the Gastroenterology Department at Hospital Beatriz Ângelo

“

Finding the cure to IBD is extremely complex. If we don't work together, we are not going to find the answer. The more we work, the more progress and better knowledge we gain – and we will find the cure.

*Professor Claudio Fiocchi*

”

## Next steps

Such meetings between IBD patients, scientists and industries are extremely important and fruitful for the exchange of knowledge, and there are already plans for a new Symposium in a few years' time.

However, in order to create something more stable and keep the patient community more up to date of what is going on in the realm of research also between these events, EFCCA is in the process of developing an online observatory.

The idea of the observatory was originally thought for keeping EFCCA's mapping project updated, but it could be expanded to also cover research projects in EFCCA's member associations. Professor Fiocchi, who closed the Symposium, said in his closing that

the involvement of patients in research is important as patients tend to be far more committed and far more honest than doctors.

His message to physicians was "If you're a physician, your commitment to improve the patients doesn't stop in the office, it goes beyond that", and his message to patients was to push the physicians into further involvement and helping more.

The research for finding the cure to IBD is, in Professor Fiocchi's words, "extremely complicated and complex. If we don't work together we are not going to find the answer.

The more we work, the more progress and better knowledge we gain – and we will find the cure."



# Take home message

The most important message, brought up in almost every speech, was the importance of involving patients in research in order to ensure that the patients' needs and priorities are reflected. Team work is needed to find answers to complicated questions in IBD research, and patients must be an integral part of the team; they see things from a perspective that the scientific community might not always think about.

Strengthening and promoting the collaboration and exchange of know-how between the patients and the scientific community is the key to success as it allows to create synergies and develop strategic research projects.

Another empowering message for patient associations was that everyone can make a difference. It was also clear from the projects presented that IBD patient associations, regardless of their size can be involved in important, prominent research projects; even small associations can make a change. Everyone is needed – and everyone can make a difference.

## ANNEX 1

List of research projects presented at the Symposium

### CLUSTER 1: NEW CHALLENGES BEYOND ORIGINATORS AND BIOSIMILARS

- Alexandra Gliati, Hellenic Society of Crohn's Disease and Ulcerative Colitis Patients, HELLESCC, Greece: Necessity of vaccination of IBD patients on treatment with immunosuppressants and on immunomodulators;
- Malgorzata Mossakowska, Polskie Towarzystwo Wspierania Osób z Niewoistymi Zapaleniami J-ellita, Poland: Quality of life related to oral, subcutaneous, and intravenous biologic treatment of IBD;
- Salvatore Leone, Associazione per le malattie infiammatorie croniche dell'intestino, AMICI, Italy: The burden of IBD in Italy: direct and indirect costs;
- Richard Stein, The Crohn's and Colitis New Zealand Charitable Trust, New Zealand: Reducing the growing burden of IBD in New Zealand;

### CLUSTER 2: PATIENTS' PRIORITIES AND UNMET NEEDS ON RESEARCH

- Adam Elgressy, The Israel Foundation for Crohn's Disease and Ulcerative Colitis, Israel: Post-traumatic stress in Crohn's disease and its association with disease activity;

- Dusan Baraga, Društvo za kronično vnetno crevesno bolezen, KVCB, Slovenia: Epidemiology of IBD in Slovenia;

- Olivia Hahn & Steffi Fischer, Deutsche Morbus Crohn / Colitis Ulcerosa Vereinigung, DCCV, Germany: PACED: Evaluating the efficacy of DCCV's patient education program;

- Anne Buisson, AFA Crohn RCH France, France: Mikinautes - dietary factors for relapse in pediatric IBD patients;

### CLUSTER 3: PATIENT-CENTERED RESEARCH AND CLINICAL TRIALS: WHAT DO PATIENTS NEED?

- Tineke Markus-de Kwaadsteniet, Crohn en Colitis Ulcerosa Vereniging Nederland, CCUVN, The Netherlands: Impacts of perianal disease and faecal incontinence on quality of life and employment in 1092 patients with IBD;
- Alejandro Samhan, Asociación de enfermos de Crohn y Colitis Ulcerosa de España, ACCU, Spain: Immune-mediated inflammatory disease (IMID) and its impact on working life;
- Wayne Massuger, Crohn's and Colitis Australia, Australia: National IBD Audit of 71 Australian hospitals;
- Helen Terry, Crohn's and Colitis UK, The United Kingdom: Living well with IBD: Optimising management of symptoms of fatigue, abdominal pain, and faecal urgency/incontinence via tailored online self-management – the IBD-BOOST programme;

## ANNEX 2

Short biographies of the moderators

### Adrian Saftoiu



Professor Adrian Saftoiu, MD, PhD, MSc, FASGE is the Scientific Director of the Research Center of Gastroenterology and Hepatology, University of Medicine and Pharmacy Craiova, Romania. He graduated in 1995 in the Faculty of Medicine, University of Craiova, and specialized in internal medicine and gastroenterology.

He has received intensive training in advanced diagnostic and therapeutic endoscopy, with emphasis on endoscopic ultrasound (EUS) and endoscopic retrograde cholangiopancreatography (ERCP), in several centers, incl. University Hospital Aarhus and Gentofte University Hospital, Denmark.

From September 2012, he holds a position of Visiting Clinical Professor at the Department of Endoscopy, Copenhagen University Herlev Hospital, Denmark.

He has published over 160 scientific articles and 14 books and book chapters, peer-reviewed articles for several high-profile journals and is member of the Editorial Board of Journal of Gastrointestinal and Liver Diseases and Visible Human Journal of Endoscopy and other indexed journals.

His research interests include hybrid fusion imaging techniques, diagnostic and therapeutic EUS, and natural orifice transluminal endoscopic surgery (NOTES and EUS-guided NOTES procedures).



### Ron Shaoul

Professor Ron Shaoul, MD, has been the Director of the Pediatric Gastroenterology Institute at Ruth's Children's Hospital, one of the largest of its kind in Israel, since 2009. He has graduated from the Rappaport Faculty of Medicine at the Technion-Israel Institute of Technology. He completed his internship and residency in Pediatrics at Bnai Zion Medical Center and a clinical fellowship in Pediatric Gastroenterology & Nutrition at the Hospital for Sick Children in Toronto, Canada. He is a Clinical Associate Professor in Pediatrics at the Rappaport Faculty of Medicine and participates actively in a wide range of clinical and basic research projects and initiatives. His main research interests are in probiotics and prebiotics, different aspects of pediatric inflammatory disease and pediatric endoscopy. Prof. Shaoul is a member of the European Pediatric Inflammatory Bowel Disease Working Group, has authored about 140 peer-reviewed articles, and is a reviewer for prestigious pediatrics and gastroenterology journals.



### Gerhard Rogler

Professor Gerhard Rogler, MD, is Professor of Gastroenterology and Hepatology and Head of the Department of Gastroenterology & Hepatology, Zürich University Hospital, Switzerland.

His main research interest is translational research to better understand the unmet needs in the IBD field, especially in terms of intestinal stricture and fistula formation.

His research group has developed new models for intestinal fibrosis and achieved a novel understanding of fistula pathophysiology.

Professor Rogler has authored over 450 peer-reviewed articles.



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