

# EFCCA MAGAZINE

European Federation of Crohn's and Ulcerative Colitis Associations

May 2020



**THANK YOU TO ALL HEALTH CARE  
WORKERS AROUND THE WORLD FOR THE  
EXTRAORDINARY WORK YOU ARE DOING!**

*EFCCA and the IBD patient community*

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# The unpredictability of life

The global impact of COVID-19 has been overwhelming and without pause, accelerating at lightning speed, changing our lives and our way of seeing the world.

In recent months, unfortunately, the philosophy of our organization, which is to create spaces for meeting, for dialogue between the various associations and all the interlocutors, has also had to change.

EFCCA's participation in medical congresses and meetings is an important occasion to reinforce this work and allows us to network with physicians, healthcare providers, and stakeholders in order to discuss common objectives and ideas for collaboration in particular as concerns quality of care.

We have rapidly moved across a graded series of responses designed for emerging pandemic viruses and are now working in a different way. We decided, due to lockdowns that are affecting several European countries, to cancel our General Assembly that was scheduled for the 30 and 31 of May 2020 in Tallinn, Estonia. Instead we will hold a virtual meeting.

As you know, this month we are marking World IBD Day and within the context of this pandemic it is even more important to support and work with patient communities that are facing a particularly challenging moment.

The theme for this year - and according to our EFCCA strategy plan - is to raise awareness around the issue of Work and IBD. Some of the measures applied by governments to control the pandemic clearly show that having flexibility at the workplace and - when possible - teleworking can have an overall benefit to our society.



With this in mind taking into consideration the needs of people with chronic diseases at work is a first step into the right direction. We are also trying to collect data that will allow us to better understand how this current situation has impacted the lives of the people we support.

For this reason, we have launched a survey in order to better understand the concerns and fears of patients with Inflammatory Bowel Disease in the context of this pandemic. This survey investigates concerns, fears, and management of IBD patients during the current health emergency related to COVID-19 infection.

The first form of participation is to seek advice on certain topics. Therefore, it is strategically important for EFCCA to collect data through surveys that allow us to highlight critical issues and develop projects that represent solutions that open a window on a future world.

We talked about the future during the recent Symposium on Digital Health and Data collection that we organized during the ECCO Congress on 14 February 2020.

The symposium, for the first time, convened representatives from the IBD patient community, physicians/Health Care Providers and the pharmaceutical industries to initiate an open discussion on how digital technologies can bring benefits and opportunities to all, a very current theme at this time when the technology will also be used to trace and miniaturize contagions from Covid19.

To imagine the future, to be innovative, to truly embrace the challenges we face, we need to anticipate the transformations that the world is experiencing. The digital structures we create now will be the skeleton on which, after this emergency, will rest our ability to react to future viruses and future emergencies, but also the way in which we will manage chronic diseases.

We are experiencing an emergency that we will certainly be able to control in the coming months, thanks to scientific research and the high quality of healthcare personnel worldwide.

We need everyone's collaboration and we are sure that everyone will be able to take this opportunity. At the same time, a question naturally arises: why, as a community, citizens, and Institutions, must we wait for there to be a danger of collective extermination to take action towards a synergistic collaboration to solve problems and improve?

United We Stand,  
Salvo Leone  
EFCCA Chairman

**“To imagine the future, to be innovative, to truly embrace the challenges we face, we need to anticipate the transformations that the world is experiencing.”**

# Survey on COVID-19 IBD patients' perception

The current state of emergency related to the coronavirus (COVID-19) pandemic represents a difficult period for both patients and doctors, as we face a new enemy, of which little or nothing is known, and which requires everyone's collaboration to overcome the problem. For this reason, EFCCA has carried out a survey in order to better understand the concerns and fears of patients with Inflammatory Bowel Disease (IBD) in the context of this pandemic.

The survey has been co-designed with Pr. Silvio Danese Head of the IBD Center at Humanitas University Hospital in Milan and was originally thought for the Italian IBD patient community, given the particularly serious situation in Italy. After a quick consultation with the EFCCA Board it was decided

to involve all its members and publish the English version immediately.

Thanks to the prompt reaction of many associations and volunteers, 11 translations of the survey have been made and published and we had many positive reactions.

## OVERVIEW

### 3815 PARTICIPANTS:



72% female  
28% male



41 y average age



40% live with children



18% live with elderly



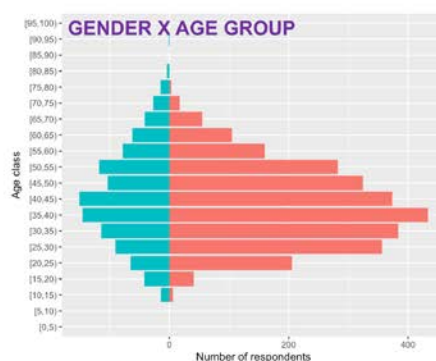
2007 average year of diagnosis



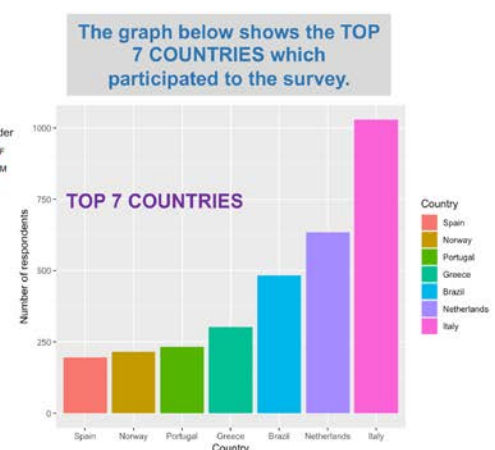
58% Crohn's disease  
40% Ulcerative colitis  
2% Indeterminate colitis



37% private employee  
21% public employee  
12% student  
12% unemployed  
12% freelancer  
6% retired



The graph above shows how females represent the majority and overall both genders belong to the 40-45 age class.



PARTICIPANTS' CHARACTERISTICS N=3815 (+/- 0.05%)

The main objective of this survey was to collect general information on how the COVID-19 pandemic is affecting the IBD patient community.

We are aware that this survey is not able to capture all national differences and sensitivities, however, we hope that with the effort of all of us we can get a general picture which will help us to better support people with IBD.

The survey has now been closed and EFCCA will inform its network as soon as we have the results analysed.

**“EFCCA has carried out a survey in order to better understand the concerns and fears of patients with Inflammatory Bowel Disease (IBD) in the context of this pandemic.”**

## EFCCA Annual General Meeting

It is with great sadness that the EFCCA Board has decided to cancel the General Assembly that was scheduled next 30 and 31 May in Tallinn (Estonia) due to the increasing concerns about the coronavirus (COVID-19) spread and the progressive and unpredictable lockdown that is affecting countries around the world.

It is a challenging moment in our 30-year history and we have never been faced with a similar situation.

In order to fulfil the institutional part of our General Meeting required by the law, EFCCA will organize a virtual meeting on Saturday 30 May to give all EFCCA members the possibility to participate and vote on our reports and elections to the Executive Board.

The health and safety of the EFCCA family is and will always be our main priority and the EFCCA Board wants to avoid any risks to organise a large event that brings together patients with chronic conditions from different countries and continents.

Despite the difficult situation and the concern for the health and wellbeing of all of us, we look forward to welcoming our delegates virtually on May 30<sup>th</sup> 2020.

# World IBD Day 2020

## Make IBD work!

Worldwide, ten million people live with Crohn's disease and ulcerative colitis, conditions known as Inflammatory Bowel Disease (IBD). World IBD Day is marked on 19 May each year and is led by patient organisations representing over 50 countries. The European Federation of Crohn's and Ulcerative Colitis Associations (EFCCA) has decided to focus this year's World IBD Day efforts on Work and IBD.

### Why Work and IBD?

With IBD on the rise and mainly affecting young people of working age we want to raise awareness of the impact IBD has on a person's professional life. Many people with IBD want to and are able to successfully work.

Studies have shown that good quality work has a positive influence on overall wellbeing. With some comprehensive strategies at the workplace, a better understanding of the disease and a supportive environment we can make IBD work!

Especially in this difficult time where the world is facing the COVID-19 pandemic, it is more than ever important to support and cooperate with patient communities.

We have seen that work measures that have been put in place by many national authorities such as for example teleworking or flexible working hours can have a positive benefit for all.



**WORLD IBD DAY**  
19 MAY

# Make IBD Work!

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

#makeIBDwork  
#worldibdday2020



Our key messages for World IBD Day are:

**Comprehensive policies and strategies** at the workplace that take into account the situations of people with chronic conditions such as IBD have an overall positive impact not only on the patient but society at large.

Direct and indirect costs of IBD can be reduced by better **prioritizing effective IBD treatment**.

There is a direct **link between employment and its positive effects** on the general well-being of a person.

Furthermore, we have collected information and material as well as good practise examples and studies from our member associations that are looking in details at the subject of Work and IBD.

For more information please visit:

[www.efcca.org/en/projects/world-ibd-day-2020](http://www.efcca.org/en/projects/world-ibd-day-2020)

In the lead up to World IBD Day we will aim to raise awareness around this topic through a **social media campaign** highlighting stories of people with IBD and their experiences in the workplace as well as sharing inspiring good practices and examples of a good employers/employee work relationships.

We will also be working with other IBD sister organisations such as Crohn's and Colitis Australia, Canada, US etc. to share our European efforts on this topic worldwide.

### Purple landmarks

We will continue to collect and share information about patient association's efforts to raise IBD awareness by highlighting famous buildings and landmarks in purple. The World IBD Day Website will be updated as information is coming in.



We will also share on our social media and will use the hashtag #worldibdday2020.

More info: <https://worldibdday.org>

# EFCCA Symposium

## Multi stakeholders on digital health and data collection meet for first time

The European Federation of Crohn's & Ulcerative Colitis Associations (EFCCA) convened representatives from the IBD patient community, Health Care Providers and the pharmaceutical industries to initiate discussions on how digital technologies can bring benefits and opportunities for all.

The multi stakeholders met at the Symposium on Digital Health and Data Collection organised by EFCCA which took place on 14 February during the ECCO 2020 Congress in Vienna.

"The digital "revolution" in health care as well as the data collected from patients, can represent an opportunity to achieve a more harmonic combination between the quality of care and quality of life data. Collecting and analysing data can become a powerful and unique way to achieve earlier diagnosis, better care strategies and identify patterns in health outcomes in partnership with medical societies and all relevant stakeholders" said Salvo Leone, EFCCA chairman, during the opening of the symposium.

Led by patient organisations the symposium aimed to gather perspectives from all the relevant stakeholders including Physicians, Health Care Providers and the pharmaceutical industries.

In his keynote speech, Professor Claudio Fiocchi from the Cleveland Clinic (USA) proposed an integrated, holistic approach which holds significant promise for improving both our understanding and treatment of IBD.

He stipulated that data including biomedical big data has become one of our most valuable resource and by merging computing and medical technologies, we will see new breakthroughs for inflammatory bowel disease.

The ensuing speakers from the patient community, medical and pharmaceutical industry community highlighted several issues that need to be taken into consideration in these discussions. They include data collection and data protection, equal access to digital technologies, patient involvement, data ownership, standardisation of data and interoperability amongst others.

The Symposium has been a unique meeting in bringing together major stakeholders and to gain useful insights into the variety of aspects to be considered in order to have a meaningful exchange of ideas and common strategies.

EFCCA strives to continue with this dialogue involving also further stakeholders such as the payers (through the International Association of Mutual Benefit Societies (AIM) as well as the regulators such as the European Medicines Agency.

We strongly believe that such a multi stakeholder approach is needed in order to create synergies and ensure that digital technologies are developed in the most efficient and effective way whilst taking into consideration their relevance to patients.

A full report is available on our website  
[www.efcca.org](http://www.efcca.org)

# European research programs and projects: how can patient organisations play a role?

Over the past years, EFCCA has been investing more resources in exploring the chance of being involved in European projects. This orientation is also in line with recommendations from our members; the EFCCA Board and staff have started to collect, monitor and sometimes select some potentially promising partnership opportunities with some first positive results.

Our association is thus increasingly perceiving the need and opportunity to benefit from “European funds” or “European projects”.

They are rightly considered important resources to finance projects, activities and innovative practices at any level (international, regional and local level) and can offer a more balanced combination in the collection of resources and facilitate exchange and know-how in several domain areas like research, education, networking and building peer to peer partnerships.

The first big challenge has been the identification of budget lines (grants) that could fit with our identity, strategy, and available professional resources. Organisations like ours have been very often applying for grants issued from stakeholders and industries and have extremely limited experience when it comes to partner or lead other types of initiatives.

Our ethic and transparency codes have been the backbone of our multi-stakeholder approach to funds, however, particularly at a time of economic crisis, working and attracting resources in a coordinated way is getting more and more challenging.

Collecting the financial resources needed from different stakeholders for any single project is a very tantalising exercise and we can sometimes run the risk of not reaching the necessary resources and therefore of not starting some of our planned initiatives.

## Innovative Medicine Initiative - IMI - Horizon 2020 Programme a “vague” and “distant” reality?

Over the past few years, it appeared evident that one of the most suitable opportunity was coming from the IMI initiative within the framework of the Horizon 2020 Programme. The Innovative Medicine Initiative – IMI is an EU public-private partnership funding health research and innovation.



**Horizon 2020**  
European Union Funding  
for Research & Innovation

Its programming period (2014-2020) is nearly at the end, however, EFCCA has been involved in some of the calls for proposals and our experience is growing. For many years, patient involvement in research was restricted to participating in clinical studies and trials as research subjects.

Today, it is widely recognised that patients can and should be much more involved in all aspects of research, including study design, communication, and ethics.

At the same time, researchers and medical societies, in general, are now aware that patients bring unique knowledge and skills to projects which can help to improve the quality of research.

This was the line indicated by IMI and followed by EFCCA and we have thus been able to become a stronger partner in some Consortia\* in which we have been included. We are currently involved in the IDEA-FAST project led by Newcastle University and the ImmUniverse project led by Humanitas University, Milan. We are also involved in a new application for the PRECISE project led by the Sorbonne University, Paris.

We have just started our journey, but we believe that by participating in research projects we could influence research by creating stronger connections with our community priorities and unmet needs. Depending on projects we can influence study design, make clinical studies more patient-friendly, or provide patients' unique perspectives on the benefits and risks of certain drugs or medical devices.

Being eligible to receiving funds is giving us the chance of actively participating in innovative projects, being part of networks and working with leading researchers from academia and industry.

And finally, through involvement in these projects we have access to the latest science, being able to pass the most innovative developments achieved to our wider patient community.

We started from smaller roles and tasks such as dissemination of results and active participation in events where outcomes were presented.

We are now playing a more active role when it comes to clinical trial design and, as presented in another article of our magazine, we are ready to lead a work package\*\* fully centered on patients and patients' needs and priorities.



Luisa Avedano,  
EFCCA CEO

\* Consortium: the usual form of partnership set up to define private/public partnership in IMI: alongside the lead partner, the Consortium is made by all the partners that sign the grant agreement and sit as equal members in the management/implementation of the projects. Members of the Consortium are Small and Medium Enterprises (SME), Academia, Regulators, Payers, and Industries.

\*\* The project is divided into Work Packages (according to its structure and objectives).

# Patient perspectives on the perceived effects of smoking on IBD

A survey on the perceived effects of smoking on Inflammatory Bowel Disease was available on the EFCCA website from November 2019 to March 2020. The detrimental effects of smoking on Crohn's disease are well known, as are the conflicting data of the effect of smoking on Ulcerative Colitis. Moreover, there is little patient-centered research assessing patients' perceived impact of smoking or nicotine use on their Inflammatory Bowel Disease.

The purpose of this study is therefore to investigate patients' perceived impact that smoking and/or nicotine use has on their IBD symptoms and progression. Over one thousand patients (65% female and 35% male) with Inflammatory Bowel Disease completed

the survey that was available in 9 languages (English, French, German, Spanish, Portuguese, Italian, Greek, Finnish, Slovenian).

The analysis of the data is not yet available, and the results will be published as soon as possible.

EFCCA would like to thank all participants and is looking forward to making the results of this survey public.

This initiative was the result of a collaboration between Nantes University Hospital, IBD Center, Department of Gastroenterology, Humanitas Clinical and Research Institute in Milan. The research was solely sponsored by Philip Morris International (PMI) and coordinated by LINKT Health. The sponsor had no role in data analysis, or preparation of the manuscript.

# Fistula survey: complex perianal fistulas and quality of life in Crohn's disease

The patient survey was carried out by EFCCA in cooperation with the pharmaceutical company Takeda in 2019 to find out the impact of complex perianal fistulae on quality of life from Crohn's disease patients' perspective. Its aim is to provide valuable insights into the life of a patient with perianal fistulae.

It has been developed in cooperation with both IBD experts and patient representatives and included questions about diagnosis, symptoms experienced, and the impact of the condition on quality of life in different areas – personal relationships (spouse, family and friends), work, and social life.

It was available on the EFCCA website in several languages of the EFCCA membership and was closed at the end of December 2019.

At the closing of the survey, over 800 respondents with Crohn's disease had participated. More than half of the respondents suffered from perianal fistulas.

A concept of the survey was introduced as a poster at the ECCO Congress in Vienna on February 14, 2020. The poster and the survey raised a lot of interest and many patients, doctors and researchers are eagerly waiting for the final results.

EFCCA is working to identify a team of experts that will be working on the analysis and the statistics of the data and preparing a scientific publication based on the results. Full results will be available later this year.

# Patient perspective on the impact of complex perianal fistulas in Crohn's disease on quality of life: Introducing the concept of the patient survey conducted in Europe

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## Background

- Perianal involvement in Crohn's disease (CD), including fistulas, ulcers, abscesses, strictures and cancer, can lead to a significant, occasionally debilitating impairment in the patients' short- and long-term quality of life (QoL)<sup>1</sup>
- Perianal fistulas can cause symptoms such as faecal incontinence, rectal pain, swelling and fever, which may significantly affect a patient's social performance, sexual function and normal life activities<sup>2,3</sup>
- Fistulas are a relatively common CD complication: approximately 35% patients with CD have at ≥1 fistula and the majority of CD fistulas are complex<sup>1,4,5</sup>
- Despite this, few studies have assessed the impact of complex perianal fistulas (CPF) on the QoL of patients with CD from the patient perspective

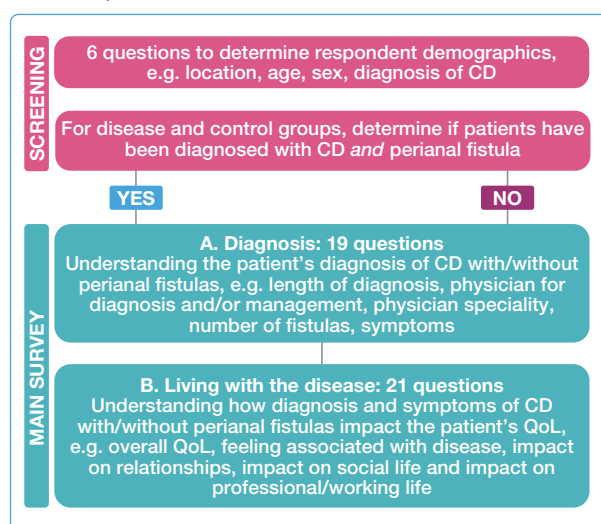
## Objective

- This survey aims to assess the impact of perianal fistulas in CD on patients' QoL in Europe

## Methods

- A survey assessing the effect of CPF on the QoL of CD patients was developed by patient representatives and medical experts
  - It consisted of questions on patient demographics and questions relating to history and activity of CD with/without CPF, as well as the self-reported impact on QoL, including the impact and restrictions on close relationships and social life, sexual activity, professional life and absence from work (**Fig. 1**)
- The survey was launched online on the European Federation of Crohn's & Ulcerative Colitis Associations' (EFCCA) website on 15 July 2019 and remained open until 31 December 2019
  - The link to the survey was shared to national inflammatory bowel disease patient associations through the EFCCA network
  - Both CD patients with and without CPF were invited to participate in order to create a control group of patients for data analysis
  - The self-selective, anonymous survey was offered in English, French, German, Greek, Hebrew, Italian, Polish, Portuguese, Romanian, Spanish and Slovenian

**Figure 1. Survey structure used to assess the impact of perianal fistulas in patients with CD**

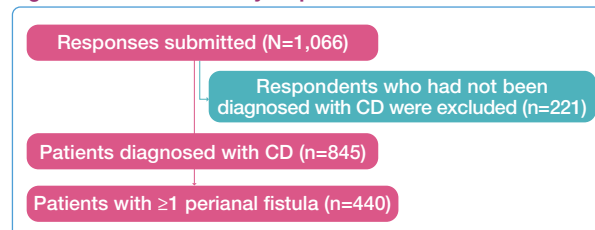


CD, Crohn's disease; QoL, quality of life.

## Results

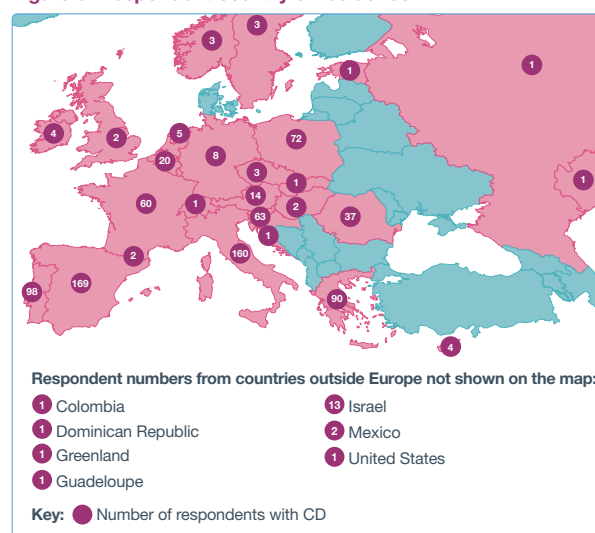
- In total, 845 patients diagnosed with CD participated in the survey (**Fig. 2**) from 33 countries around the world (**Fig. 3**)
  - 66.7% (n=564) patients were female
  - In addition to CD, 52.1% (n=440) of the respondents also suffered from ≥1 perianal fistula

**Figure 2. Number of survey respondents**



CD, Crohn's disease.

**Figure 3. Respondent country of residence**



CD, Crohn's disease.

## Conclusions

- The data collected will allow a comparison between CD patients with/without CPF, and between patients in different countries, in important patient-relevant aspects of QoL assessments
- There are some limitations of the survey:
  - Selection bias may have an impact on the data as the survey is self-selective, and only available online and in a limited number of languages
  - Recall bias may also have affected some responses due to the retrospective nature of a number of questions
- The collected data will be statistically analysed thoroughly in 2020
  - Initial analysis of the survey responses showed that more than half of responders had ≥1 perianal fistula
- The results will provide valuable insights and a deeper understanding of the often unspoken burden in the life of patients suffering from CD with CPF, and may potentially aid treatment decisions for these patients

## References

1. Ingle SB, Loftus EV. The natural history of perianal Crohn's disease. *Dig Liver Dis* 2007;39:963–969; 2. Rencz F, Stalmeier PFM, Péntek M, et al. Patient and general population values for luminal and perianal fistulising Crohn's disease health states. *Eur J Health Econ* 2019;20:91–100; 3. Marzo M, Felice C, Pugliese D, et al. Management of perianal fistulas in Crohn's disease: An up-to-date review. *World J Gastroenterol* 2015;21:1394–1403; 4. Scharl M, Rogler G. Pathophysiology of fistula formation in Crohn's disease. *World J Gastrointest Pathophysiol* 2014;5:205–212; 5. Schwartz DA, Loftus EV, Tremaine WJ, et al. The natural history of fistulizing Crohn's disease in Olmsted County, Minnesota. *Gastroenterology* 2002;122:875–880.

## Acknowledgements

This study was a collaboration between EFCCA and Takeda Pharmaceuticals, and Takeda Pharmaceuticals provided funding for the facilitation of the study. Medical writing assistance was provided by Syneos Health Communications, funded by Takeda Pharmaceuticals.

## Disclosures

AS has received personal fees from Takeda, Pfizer and Sofar. SL has nothing to disclose. LA has received personal fees from Pfizer. DB was an employee of Takeda at time of abstract submission. She is now an employee of F. Hoffmann-La Roche Ltd.

# EFCCA Academy on Clinical Trials

The EFCCA Academy is due to continue IBD patient education this year. After the successful first round of training on communication and the meaning of advocacy in general, that was delivered in 2018-2019, for 2020 EFCCA has been preparing a comprehensive training focused on Clinical Trials.

The choice of topic, i.e. Clinical Trials, is based on the assumption that patient engagement is increasingly recognized as essential to integrating the patient voice in the design and development of research on medicines.

With skills, knowledge and competences patient can play a proactive role in defining unmet needs and have a greater influence on the choices of decision-makers, such as political, economic and social institutions. Particular in this moment where the world is facing a pandemic and industries are working hard to find clinical solutions we believe that patient education of this subject is of paramount importance.

Our original plan was to organize the training through face to face and online sessions to optimize costs and to be able to expand this educational opportunity to as many patients/students as possible.

However, given the current situation due to the COVID-19 pandemic our face to face training, foreseen to take place during the EFCCA General Assembly this May 2020, will unfortunately not take place within this time framework.

Instead we are putting more efforts in the development of the online sessions which will consist of three modules within a time frame of one year. The chosen topics/modules are the following:

1. Clinical trials: basics;
2. Breaking the myths around clinical trials;
3. Diving deeper into clinical trials.

The online modules will be divided into learning sessions of no more than 15 minutes each. Teachers will follow a specially prepared teaching structure and will present the chosen topics in video clips. At the end of each video the participant will be given a set of 4-5 test questions to see what he/she has learned. After successfully responding to the questions, the participant will be able to move on to the next session.

There will be a set of selection criteria for participation in this training and more information will be shared once the training modules have been completed.

For more information please contact Sanna Lönnfors  
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# A very special European Youth Meeting for 2020

Every summer since 1998, a very special event takes place amongst the EFCCA community in a different location each year. It's the European Youth Meeting (EYM), the EFCCA event for the under 30s patients. But what is it exactly? A holiday? A never-ending lecture? A bird? A plane?....Is that superman over there?

To some people's surprise, the EYM isn't a holiday for IBD patients. It's an event where young delegates from members of the EFCCA associations gather to share their work and collaborate in the creation of new projects that will have an impact on young IBD patients' lives.

Over two days, young delegates present their work within their national association, participate in workshops, attend a lecture and experience the local culture. Before saying goodbye, the group of delegates elects seven of the attendees to establish the EFCCA Youth Group (EYG) board, where each member seats for a 2-year term, that will continue working on the topics discussed during the Youth Meeting's workshops until the following summer.

Further than offering the chance to work on improving the lives of young IBD patients across Europe with long-term programs, the EYM is also a good opportunity for delegates to encounter others with similar health and life issues.

Over the years, many young delegates witnessed the big-family spirit that prepares young EFCCA members to be future leaders and help them take further actions back in their national associations.

This year's edition of the EYM will unfortunately not be happening face-to-face due to the recent sanitary crisis but, rather than giving up on it, we are currently looking into different kinds of solutions to provide the closest online experience on the same date, August 8<sup>th</sup> 2020.

Since two members are reaching the end of their terms, there will be two open positions to integrate the EFCCA Youth Group. More information about the platform, the election and agenda will be available soon. We may not be able to hug each other at the end but we will for sure keep the EYM spirit.

EFCCA Youth Group

# Previous experiences from the European Youth Meeting

“Last year it was my first experience with the EFFCA youth meeting. I met other delegates in Brussels. At first, I was scared and insecure... How will I be able to include myself in this group? But all of them were so nice and such beautiful people that I didn't have any problem with my insecure feelings. We were joking, making plans for EFFCA, we had a presentation of our national associations and I won as the best presentation. WOOOOW, I was so surprised! On Friday and Saturday evening we went out for dinner and had a little chat. When everything was over, I said to myself that it was one of the most amazing experiences I ever had and I can't wait to see them again.”

*Barbara Korosec,  
Slovenia delegate, first time coming.*



“Last summer was my last participation in an EYM. After four years of involvement, it's time for me to move on and pursue my fight for IBD cause in a different way. However I will not leave the EFCCA family, I am becoming the new French delegate for EFCCA. There is more than one thing I will remember from my EYM experience but the main one is the people. I met such great persons during these meetings, coming from countries all over Europe and even beyond. Despite the disease, people are optimistic, kind and supportive. For sure it's a wonderful value for our IBD community. The EYM gave me the opportunity to figure out the diversity in IBD associations. Some of them are well structured with employees and financial resources, some others are a handful of volunteers with their energy and ideas as main resources. However, even if we don't have the same weapons in our hands, we all have the same goal: bring support to the IBD community and find a cure for these diseases. I will never forget this experience because it brought me so much, as a person and as an IBD association representative. For those who have the opportunity to attend an EYM, I would highly recommend it. It's really worth it!”

*Bastien Corsat, French delegate,  
former EYG Leader.*

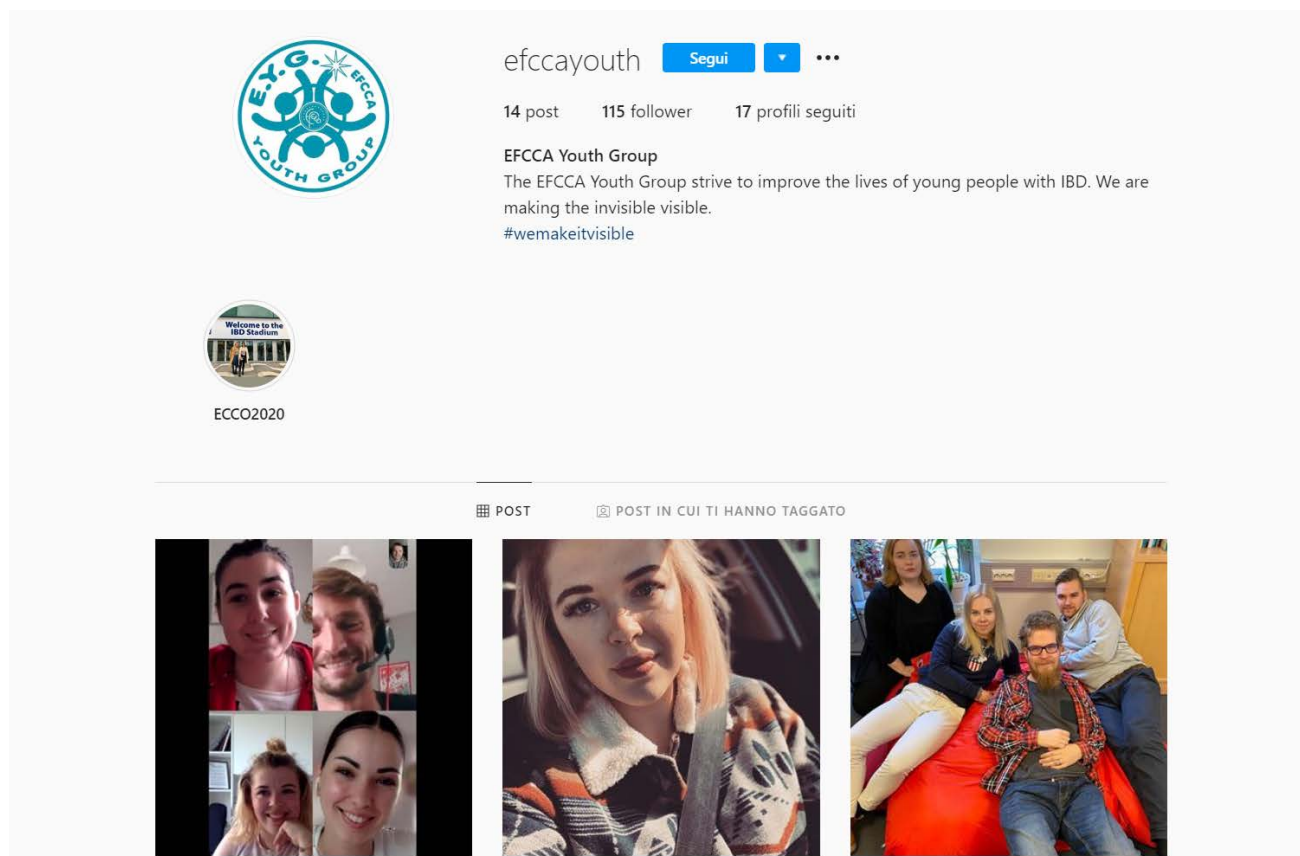
# New Instagram-page

The EFCCA Youth Group has been busy in these couple of months. We have improved our communications and worked on our projects. This and last year the EFCCA Youth Group has raised its communication to the next level. We strive to keep all our social media followers updated about what we do in the Youth Group. We also work to increase our followers so that our message reaches more people including also people who don't have IBD.

The most active and followed channel of our external communication is the Youth Group's Facebook page where we strive to keep followers updated by announcing things happening in EFCCA, post news about IBD and share other interesting articles. During autumn and winter last year, we also have been introducing members of the Youth Group board. In this way we are making our activities more transparent and are showing that behind the EFCCA's youth activity there are real, young IBD patients. Our Facebook-page has now 1152 followers and the number are constantly increasing.

We also would like to strengthen our communication with national IBD associations. Last year we established a Facebook-group for delegates of the Brussel's EFCCA Youth Meeting, where we asked opinions of participants about our projects.

By communicating with members of national associations we can make our activities more grass root level. We do our job for IBD patients around the world and the best way to do our job well is to ask what our target group really wants.



At our last face-to-face meeting in Brussels we established an Instagram-page for our Youth Group. @efccayouth has now been up over two months and we have almost one hundred followers already. At the same time we started using hashtags #wemakeitvisible and #efccayouth. In Instagram we have continued presenting members of our Youth Group, shared IBD-memes and updated things happening in national associations.

In autumn we noticed that Facebook's algorithms favours pictures and videos. This EYG season we have strived to produce more visual content instead of just sharing news and articles. For example, at Christmas we wished merry Christmas to all our followers in video format.

In the future we strive to produce even more interesting, bigger and active social media content for our channels, so those people who do not have IBD will also find our page.

That way we could spread IBD awareness and enhance the status of young IBD patients in Europe and all over the world.

## IBriDge project to be launched soon

Social media is not the only thing we have been working on. The Youth Group has been thinking for a long time how to help IBD patients in their transition phase from paediatric to adult care. We decided to establish a website, which would give information and guides about this transition phase. We call this project IBriDge.

This autumn and winter we have been collecting reliable information from different sources about how patient transfers from paediatric to adult care. We wanted to make the website's information package very comprehensive and expanded our target group from patients to doctors and families.

The planned website will tell users for example what kind of skills and knowledge young patient should have before and during transition phase, what doctors should consider during this phase and how the patient's family can support them during this time.

In a Youth Group Board meeting which took place in January 2020 we planned the content and layout for our website. IBriDge will be published and ready to use later this year.

The EFCCA Youth Group is active in these exceptional times as well. Our channels of social media are active, monthly Skype-meetings operate as before and IBriDge develops at a normal rate. Take care of yourself and people around you and remember to treat your IBD despite the situation. And remember to wash your hands.

# Slovakia

## Video discussions with other countries

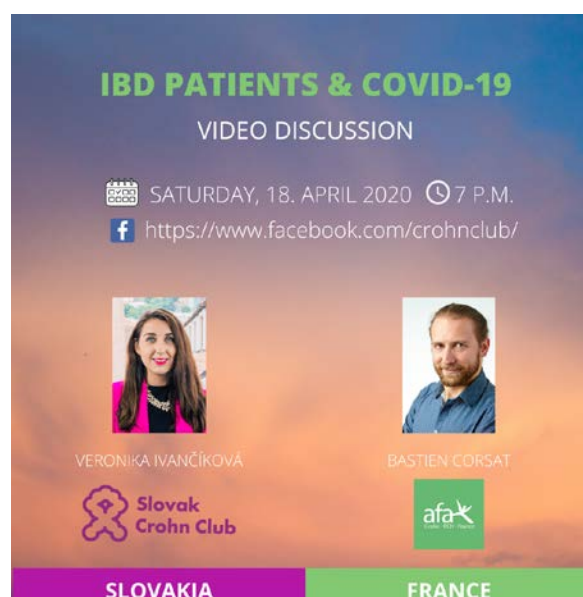
In this challenging time of the COVID-19 situation, the Slovak patient organization decided to learn more about other countries and stay in touch with IBD patients from various corners of Europe. The fact is we hear and watch enormous amounts of information about COVID-19 but we don't hear from patients themselves.

Who questioned us about our feelings and how we, the IBD patient community, are coping with the new situation? We were asked only to stay at home and protect ourselves. Of course, this is important, and we should follow official recommendations but it doesn't mean that we can cope with the situation easily.

That's how our idea was born and we realized that we can support each other even though we are so far. Thank God for the internet :)

The first video came out on Wednesday 15.04.2020 on the Facebook page of the Slovak Crohn Club and included a discussion with the Czech Republic (PACIENTI, IBD) association where we discovered that the situation with IBD patients and their perspective is very similar. Our colleagues and friends have been getting crazy too by staying at home for such a long time, but they told us that they have dedicated their time to sew masks from fabric and support each other similar to what we have been doing in Slovakia.

The second video went out on Facebook on Saturday 18.04.2020 with the French patient organization (AFA CROHN RCH FRANCE). We realized that IBD patients share the same "fear" during this situation and it is that we mostly worry about our families and relatives and of course are afraid of getting infected by COVID-19. The third video was posted on Sunday 19.04.2020 with the Estonian patient organization (IBD EESTI) where we discussed the difficult time for IBD patients who had lost their jobs or had stayed at home without any income.



This situation has been also happening in Slovakia, so we have to support each other at least via contact with our members on the phone or online.

I hope we can learn a lot from each other and support IBD patients nowadays even more by exchanging posts or videos about IBD patients themselves, not only by posting the latest information about COVID-19. Anyway, UNITED WE STAND :)

Who will be the next country to discuss this topic with me? I will be very happy to share experience from Slovakia. I am looking forward to hearing from you. Please stay healthy and smile.

Veronika Ivančíková,  
President of Slovak Crohn Club



## Spain

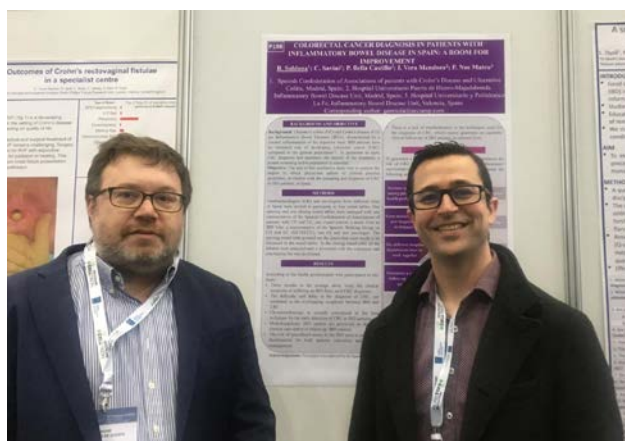
### ACCU Spain attends ECCO 2020

The IBD patient association ACCU Spain and its patient community participated in several studies that have been presented during the last ECCO Congress, the leading world congress for Inflammatory Bowel Diseases with over 7000 attendees from more than 87 different countries and which took place from 15-17 February 2020 in Vienna, Austria.

The topics of the studies presented were cancer and IBD, the follow-up patient's app called TECCU and self-medication with steroids.

Every time a patient responds to one of ACCU Spain's surveys or participates in a research promoted by ACCU, he or she is directly contributing to creating more knowledge about Crohn's disease and ulcerative colitis, its management and the way patients live with the disease.

It's an invaluable contribution and we thank our members and supporters who make such studies a success.



Poster presentation during ECCO Congress:  
Manuel Barreiro, GETECCU (left) and  
Roberto Saldaña, ACCU Spain

# New Zealand

## Parliamentary hearing on access to toilets

On November 27, Allyson (Ally) Baine, JD, a lawyer for the American Civil Liberties Union (ACLU) in the United States, and Nicole Thornton, 14-year-old Crohn's and Colitis New Zealand (CCNZ) Youth Ambassador, jointly addressed over 400 medical professionals in Wellington. In attendance at their address at the annual meeting of the NZ Society of Gastroenterology was Health Select Committee Chairperson, the Honourable Louisa Wall.

When Ally was Nicole's age, she was in a large store in a mall in Chicago, doubled over in pain, urgently needing a toilet. She was refused access to the store's employee toilet, despite pleading with the manager. Ally had an accident in the store and vowed that this should never happen to anyone else. Together with her representative in the Illinois State Legislature, Kathleen Ryg, Ally was successful in getting the first "Ally's Law" passed in the state of Illinois. Sixteen other states have since followed suit, all passing their own "Ally's Laws". These laws guarantee access to employee toilets to people with medical conditions who may need them urgently if no public toilet is available.

Nicole Thornton, for the past three years, has been trying to get a similar law passed here at home. Through her petition to Parliament and her testimony in front of the Health Committee, she has made major inroads in raising awareness about IBD. Unfortunately, we have yet to see a law in NZ, although Parliament has affirmed the need for better toilet access and encouraged businesses to cooperate.

Within the next month, Nicole and CCNZ will be launching a national campaign to encourage businesses to open their doors and their toilets to people with medical conditions. The campaign will identify store owners who will honour the CCNZ "I Can't Wait Card" with a sticker in their window (written in English and Te Reo), shown below.

Hutt City, Nicole's hometown, has been the first to endorse the campaign and will place the stickers in their city buildings. A media event surrounding this project is currently being planned.

Our goal is to see these stickers in every city throughout the country, but it will take a concerted effort to approach store owners and city councils throughout New Zealand to honour our "I Can't Wait Cards".

More on this campaign will follow over the course of the year, but we hope everyone in the New Zealand IBD community will join this effort. It will raise awareness and, most importantly, make the lives of people with IBD more livable. It would be great if this campaign spread to other member countries.

No one should have to fear going out in public to avoid what happened to Ally.

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# Romania

## Misperception of IBD Surgery

How much hope can a person have in his/her gastroenterologist when he/she is diagnosed with Crohn's Disease or Ulcerative Colitis and understands it is a chronic autoimmune disease? All hope and all life.

But, especially, when the news of a surgical intervention paralyzes our soul, how many of us did not do our luggage, cleaned through life as in a spring cleaning, as in a closet with many useless things, and we quickly gathered in a small luggage, the strictly necessary items: some important plans for the future, the thought for the loved ones, the plan for a career, passions, dreams, hopes and we lay them, as on an altar, in the hands of our surgeon.

It is not so that you tried to catch his/her every gesture, every morning, to catch a glimpse of his/her thoughts; is it not so that for a while, the whole world is reduced to one man, one woman, and you feel, perhaps for the first time in your life, that your God has another face?

Isn't it that all your prayers have a white robe and the same face?

For a while, you feel anonymous in your own life. You just wait and pray that after you wake up, you will look into the surgeon's eyes for the light to support you - the chandeliers to hang on to and step into your new life.



*Left to right: Prof. Antonino Spinelli - surgeon / Head of the Department of Colon and Rectal Surgery, Humanitas Research Hospital, Rozanno, Milan; Isabella Grosu - president of the Romanian IBD Patient Association, European Ostomy Association Executive Committee member; Prof. Cristian Gheorghe - gastroenterologist / Head of the Department I of the Gastroenterology Clinic, Fundeni Clinical Institute, Bucharest.*

We all know that very often IBD patients, in their long journey with these chronic autoimmune diseases, go under surgery that results in partial or total colon resection or interventions for abscesses, fistula or even cancer. It's estimated that around 70% of people with Crohn's disease and 25% of people with Ulcerative Colitis will need surgery during their life to help treat their IBD.

Although we have become accustomed to considering surgery as a last resort in treating IBD, specialists are now considering surgery as an alternative strategy to treat IBD.

Gastroenterologists and surgeons working together in multidisciplinary teams to find the best solution for the individual patient is considered to be a key in optimizing care for IBD patients. One significant change over the last few decades is probably the fact that involving a surgeon at an early stage of the disease is now considered good clinical practice and is part of most quality-control parameters.

However, there are still misconceptions about surgery in IBD and patients often have a refractory attitude to surgery, despite of clear evidence of improved quality of life in the operated patients.

As a beneficiary of surgery in IBD for 17 years now, I was absolutely in agreement with Prof. Antonino Spinelli, MD, PhD Head of the Colorectal Surgery Department, Humanitas Research Hospital, Rozzano, Milan, and honored by his invitation to analyze together, surgeon and patient, the "Misperception in IBD Surgery" within the educational programme, S-ECCO Masterclass in IBD Surgery, ECCO Congress 2020, Vienna.

We have shown that, statistically, there is a fairly high percentage of patients that refuse or barely accept the idea of surgery; while, shortly after surgery and recovery, these state that they have a much improved quality of life compared to the IBD flares, to the secondary manifestations of treatment, restrictive diets, limitations for daily activities to a close self-isolation or self-exclusion from social life.

After a period of adaptation to the new body scheme and a comeback to a normal life, analyzing the quality of life before and after surgery, a large number of patients declare that they would not go back to the life before the surgery and that they regret that they haven't made this decision earlier.

Conclusions?

- There is a gap of information on surgery as option in IBD;
- Misinformation leads to misalignment between preop perception/expectations and postop outcomes and quality of life;
- Gap to be filled with patient associations, counselling, multidisciplinary teams collaboration, preop psychological intervention.

And when it comes to surgery before or after medical therapy, with or without a biologic umbrella, then what counts is what is the best for the individual IBD patient. Therefore, as a promoter of the IBD Patients' needs and as a representative also of the European Ostomy Association, I have to declare that our experience shows that there is an absolute need of a team working closely: gastroenterologist – patient – surgeon since the early stages of the disease.

Following of the S-ECCO IBD Masterclass  
ECCO Congress 2020, Vienna

Hot debates in IBD Surgery  
Educational programme, February 13th

Misperception of IBD Surgery session  
Coordinated by Prof. Antonino Spinelli

*Isabella Grosu*  
*President of Romanian IBD Patient Association*  
*[www.aspiir.ro](http://www.aspiir.ro)*

# Finland

## Support for elderly patients with IBD: the “TIISE” project

There are around 50 000 IBD patients in Finland, and around 15 000 of them are over 60 years old. Furthermore, a quarter of the members of the Finnish patient association, the Crohn and Colitis Association of Finland, are over 60 years old. Traditionally, there are lots of activities and support groups for young people with IBD, while older patients – even though they are a large patient group – are easily somewhat forgotten.

The peak incidence of IBD in Finland is known to be between ages 15 and 35, but there is another peak between after the age of 60.

To better accommodate for the needs of the elderly patients with IBD, the Finnish association is starting a project for supporting them (Tukea ikääntyvän IBD:tä sairastavan elämään, ”support for elderly patients with IBD”, abbreviated TIISE).

Although the name implies otherwise, also other chronic patients – such as those with thyroid diseases – are included in the project. The project is financed by the Funding Centre for Social Welfare and Health Organisations, working under the Finnish Ministry of Social Affairs and Welfare, and executed by the Finnish Crohn and Colitis Association.

The duration of the project is three years, and it will enable peer support for elderly IBD patients both face-to-face and online. Participants are offered the possibility to join overnight meetings of 2-4 days in different parts of Finland for peer support as well as exchanging information and learning about resources and aging.

There will also be shorter one-day meetings that focus on different themes. The project was supposed to kick off in spring 2020 but is currently being postponed due to the coronavirus pandemic and will start when circumstances change.

With the TIISE project, the Finnish association wants to raise awareness regarding elderly patients with IBD.

Unlike young people with IBD, older patients may often also suffer from other health conditions and take other medications. Treating an older patient with IBD may therefore be more challenging, as the treatment needs to fit together with other medications that the patient is taking.

The project will produce material about treating elderly people with IBD to health care units and nursing homes to help their staff understand the impact if IBD on the lives of elderly patients.

For more information, contact the coordinator of the project Maria Joutsen at [maria.joutsen@ibd.fi](mailto:maria.joutsen@ibd.fi).



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# France

## Cycle to beat IBD

Laëtitia Besnard, a French champion track cyclist and IBD Patient Ambassador, broke the French national track cycling record in the women's age 40-44 category on 7 March 2020 at the National Velodrome in Saint Quentin-en-Yvelines, France. In 1 hour, Laetitia cycled the track at an average of 41 km/h, not quite reaching her personal objective of 42km/h. Laetitia is France's 2020 Master triple champion. She's hoping to take part in the 2020 Master Track Cycling Championship in Bourges, France on 20 June and after that in October 2020, if health-wise everything's fine, she'll compete in the World Master Championship.

Laëtitia has IBD. She finds that her sport is very beneficial for her health and she has been supported by a whole network of health experts to reach her goal. She approached Afa Crohn RCH France to open a fund-raising website online using her championship to raise money for IBD research.

When asked why she wanted to open this fund online, she said: "Every Euro will be given to Afa. I have had ulcerative colitis for 8 years and I decided to unveil my "invisible" disease to break the taboo, support other

IBD patients, and most of all, to show that doing sports is possible despite the disease. My last flare-up was last winter, and I had to stop competing for 4 months. Thanks to a new treatment which I started in February my UC is stable. I'm able to better prepare this track cycling attempt to reach my goal, even if fatigue and some symptoms have reoccurred since January."

*Alain Olympie and Laëtitia Besnard*



Alain Olympie, Afa CEO, was present to support our champion and he told us how he experienced this event:

“It was Saturday morning at 10:30 that I discovered this beautiful national arena in St. Quentin-en-Yvelines. All the bicycles were unloaded from the cars. It was an unusual ballet from the parking lot to the arena. People greeting each other, the cycling community is most of all a big family. Laëtitia’s friends had come, as well as her family and some Afa volunteers. The Champion warmed up over a few rounds on the track. I took advantage of a quiet moment to meet Laëtitia and humbly encourage her as I could see she was deeply concentrating. I took this opportunity to ask her for a photo. Smiling, she commented: “I prefer doing it now as I don’t know what I’ll look like at the finish line!” Off she went for an hour, we’re counting the rounds, applauding each time she’d go by and feeling the fatigue by proxy as her feat seemed so incredible. At the finish line, waiting for the judges to reveal the results was awful as they were taking their time! Laëtitia’s face was sunken and gaunt showing her fatigue and tension as she would have wanted to do better.



A rather crazy wager to support the IBD cause! Yes, with a chronic disease, one can go much further than an “able-bodied” record maker. An explosion of applause, laughs, a few tears of joy from all topped off the results! A sure bet with a new record to beat in the back of her mind, Congratulations to our Champion and IBD Ambassador.”

## Italy

# Consensus Conference

How is it possible to encourage an optimal patient proactivity and involvement in his/her own course of treatment? How can the patient be part of the healing process? These are the psycho-social welfare questions to which the Consensus Conference wants to give an answer. In the last few years science is shifting towards patient engagement and a pro-active approach where the patient becomes a co-protagonist together with his gastroenterologist of his process of improvement.

The national IBD association AMICI Onlus organized the Consensus Conference in collaboration with the Research Center Engage Minds Hub of the Catholic University of the Sacred Heart of Milan and with the National Institute of Health.

The event was a “space for dialogue and discussion” between experts coming from different professional, institutional and voluntary worlds.

The contexts considered were both the one of the adult patients and the pediatric patients.

It's also the kick off of a process to elaborate recommendations that identify practices and effective tools to promote a good practice of engagement and taking charge of psychological and social care needs for IBD patients according to a very specific approach: the standards defined on the American NIH's Consensus Development Program and the approach described in the SNLG guidelines of the National Institute of Health.

"The Consensus idea was conceived because patients ask more and more to be the focus in the healing process and this central role cannot be managed only by the referring physician, which is the gastroenterologist" says Enrica Previtali, AMICI Onlus President. "What the recommendations will have to define is a better method of taking charge of the patient from a multidisciplinary team directed by the gastroenterologist, where the psychological component is well aware and supportive of emotional and existential needs."

"The idea of a multidisciplinary approach for the management of patient with IBD" – says Alessandro Armuzzi, Former IG-IBD General Secretary – "is one of the key points of the national reference Scientific Society (IG-IBD). For a long time now our educational activities and scientific research, are aimed at the valorization of the multidisciplinary approach which see in the engagement and in the psycho-social welfare two fundamental aspects to start developing and truly making this model a reality for the management of the patient."

Researchers and doctors agree on the importance of the promotion of patient engagement in order to increase the clinical efficacy; there is a wide opening related to the consideration of psychological and social-care needs of the patients during their clinical process. However, up to now there is no consensus to the best practice for the promotion of the engagement of the patient with IBD and the taking charge of their psychological and social care needs.



The main objectives of the Consensus Conference are listed below:

- Identification of psycho-social welfare and primary psychological needs of people affected by IBD and definition of a good procedure for a social-assistance and psychological care;
- Clarification of the most appropriate time in which it is necessary to take charge of the social welfare and psychological needs of people with IBD by defining levers and obstacles of the Engagement process;
- Proposal of life's quality and monitoring rates, specific for the psycho-social welfare and engagement processes (including socio-economic elements);
- Promotion of a multidisciplinary agreement (also between healthcare professionals, patients and their families) in order to establish recommendations and guidelines for promoting the engagement and taking charge of the psycho-social welfare of people with IBD.



For further information  
[ufficiostampa@amiciitalia.net](mailto:ufficiostampa@amiciitalia.net)

## Brazil

# Nutrition intervention and COVID-19

Due to the pandemic caused by the Coronavirus, DII Brasil, in addition to encouraging everyone to follow the safety recommendations made by WHO World Health Organization, also asked Doctor Lana Claudinez dos Santos, a nutritionist member of the Scientific Council, to prepare a short article with nutritional tips to strengthen the immune system of people living with IBD. We make it clear that the article does not replace the prescription of any doctor and nutritionist and are of informative nature.

A pandemic is being faced by the world. The COVID-19 is growing and its cure is still unknown. Care is being adopted in several countries, including social isolation. Another important care that can help in preventing the disease or even its progression is a healthy

and balanced diet, which can offer all the nutrients necessary for the appropriate functioning of the body, including the fortification of the immune system and preservation of the nutritional status.

For patients with Inflammatory Bowel Diseases (IBD), care with food is essential and can contribute to the treatment of IBD and to improve the immune response.

A systematic review published in the Journal of Medical Virology (ZHANG, LIU, 2020) showed the importance of various nutrients for the immune system, such as vitamins A, C, D and E, and minerals as zinc and selenium, as well as the omega 3.

According to the authors, these nutrients play an important role in preventing infections caused by various viruses such as measles virus, human immunodeficiency virus, avian and bovine coronavirus.

Knowing the importance of these nutrients for the immune response, it is essential that patients with IBD try to consume these nutrients in their daily routine, preferring a healthy diet and greater protection for their health.

Below there is a list of nutrients related to immunity and some food to find:

- Vitamin A: meats, yellow squash, peppers (red or yellow), carrots, mango
- Vitamin C: lemon, orange, pineapple, acerola
- Vitamin D: egg yolk, salmon, beef liver
- Vitamin E: avocado, coconut, oilseeds
- Selenium: Brazil Nut, sunflower seed
- Zinc: linseed, egg yolk, oilseeds
- Omega 3: marine fish
- Proteins (animal or vegetable origin) are also important in this context, providing amino acids for the formation of new cells and better immune action



*Lana Claudinez dos Santos*

It is important that patients with IBD opt for adequate and healthy food, preferably guided by a professional, considering the particularities of the IBD and the possibly contribution of this diet, to the immune response against infectious agents, including the coronavirus.

Lana Claudinez dos Santos, Nutritionist  
MSC and PhD and Biochemistry and Immunology  
Member of the Scientific Council of DII Brasil

# Poland

## Hearts from “J-elita” Association to IBD children

For St. Valentine's Day the Polish Association Supporting People with IBD “J-elita” had a surprise for little IBD patients of Krakow's hospital and gifted them with handmade hearts and puppets.

Volunteers of “J-elita”, both adults and children with IBD, met last December in a community centre in Krakow to jointly sew several dozen heart pillows and almost one hundred owls and fishes. The meeting was a great opportunity to have fun and forget about the disease at least for a while, but the most important thing was the main goal – manufacturing as many puppets as possible. In February 2020, in celebration of St. Valentine's Day, those puppets, along with bedclothes received from sponsors, were given to little paediatric IBD patients of the University Hospital in Krakow.

“J-elita” has been cooperating with the hospital for many years, organising - for instance - art therapy meetings and Santa Claus events. The children were very happy about the gifts they'd received - there was no end to their cheers.

Did you know that St. Florian's Church in Krakow houses the relics of St. Valentine, the patron saint of lovers? They are stored in a baroque altar decorated with an 18th century painting of St. Valentine praying... for sick people. That obliges!



## “J-elita” supports IBD patients during COVID-19 pandemic

A special webpage with information about IBD and the novel coronavirus, a newsletter, free of charge phone and on-line medical and psychological consultations – the Polish Association supporting People with IBD “J-elita” does everything possible to support IBD patients during this pandemic period.

“The COVID-19 pandemic has turned our lives upside down but has also made all of us more concerned about our health and the health of our relatives,” said Agnieszka Gołębowska, President of the Board of the “J-elita” Association and mother of two daughters diagnosed with Crohn’s disease.

The everyday life of almost 60 thousand IBD patients in Poland drastically changed from one day to the next. The best Polish hospital managing IBD patients in Warsaw has been repurposed as an isolation hospital by the authorities and other hospitals that manage IBD have stopped or limited admissions. Patients couldn’t reach their doctors and clinics.

They didn’t know how to obtain prescriptions for their medications. There was also a huge deal of uncertainty in regard to the continuation of a treatment, especially in those patients under biological or immunosuppressant treatment.

In this situation the “J-elita” Association became a main source of information for IBD patients in Poland. “J-elita” addressed a letter to the National Consultant in the Field of Gastroenterology and Paediatric Gastroenterology, as well as to the Chief Sanitary Inspector for patient guidelines. That information, along with other guidelines, ECCO interviews and all important materials found on the internet were immediately published on “J-elita’s” website and Facebook page. We also mailed out this information to over 5000 recipients via newsletter.

Among other things, patients were informed that they shouldn’t stop taking their medication by their own account and that prescriptions can be prescribed by a GP during telephone consultations.

MD prof. dr hab. Jarosław Kierku, paediatric gastroenterologist who cooperates with “J-elita”, volunteered with his co-workers to provide free of charge on-line and telephone consultations for paediatric and adult IBD patients who cannot reach their doctors.

Two hospitals managing IBD patients in Rzeszów and Pozna addressed its patients via “J-elita”. Furthermore, starting April 1<sup>st</sup> “J-elita” began providing free of charge psychological consultations for those who face difficulties while in isolation during this pandemic period.

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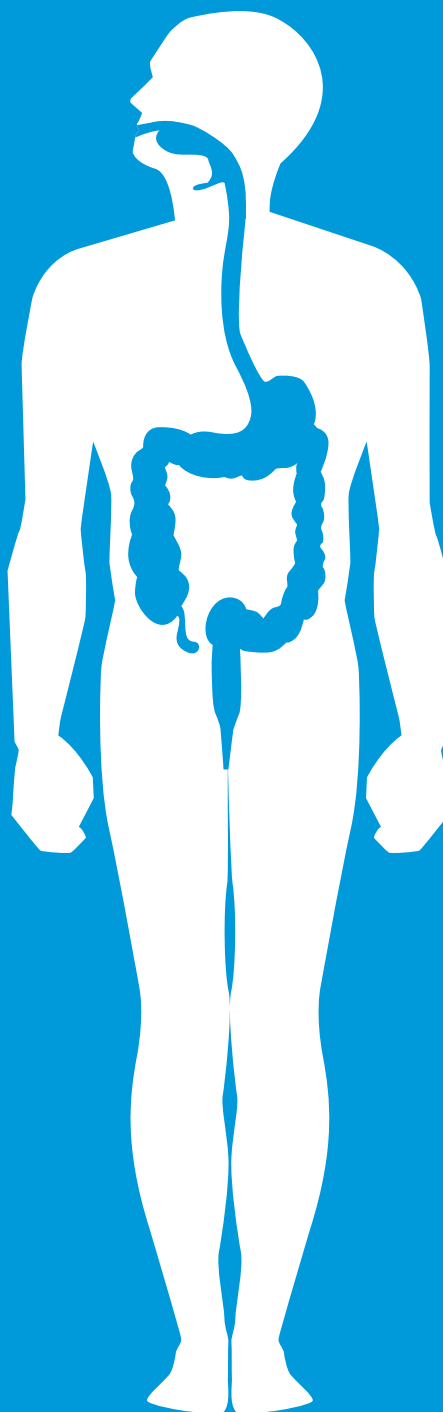
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## TOMORROW

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# The perfect storm!

## Introduction to an IBD adolescence

Adolescence... The transitional phase of growth and development between childhood and adulthood...

We can think of it only as a cycle of physical changes that will culminate in reproductive maturity, reducing it to puberty. However, it would be incomplete and even incorrect, to ignore all the psychological, social and moral development of this “phase”.

The construction of personality, who one is, who the other is and what world is this that I’m in. How do I function and how to interact with others who are younger, older or the same age? Parents, siblings, teachers, friends and acquaintances, and all of the others too.

And discovering all this in the midst of so much change. School change, colleagues change, teachers change, love and friendship relationships change, adolescents, friends and sometimes even parents change.

And everything is always so intense. Every time, everything “for now” and “forever”.

Like the choices we have to make! A thousand choices that adults either choose on our behalf, or that “from out of nowhere” they throw at us and want us to know how to do it. Of course, we should have enough emotional self-regulation to face it “lightly and naturally”. Something they describe as “it’s going to define your life forever! So, decide what to do with your life!”

Oh, the irony...

In this context of daily challenges in which all the “actors” feel insecure, the adolescent does not even know what he or she is feeling or how to act, we can think of Inflammatory Bowel Disease (IBD) as the flood that makes the cup overflow.

Crohn’s disease and ulcerative colitis are worldwide the most common intestinal pathologies in adolescents, with a detrimental impact on their health-related quality of life.

Can you imagine how much the symptoms of an Inflammatory Bowel Disease (IBD) can interfere with our daily lives? Can you imagine yourself as a teenager again, and add what you feel today with your illness, to everything that happened at that time?

It’s the “perfect storm...”

For example, a teenager with Crohn’s disease (CD) may have serious concerns about his height, delays in his puberty or general development, with fatigue, lack of energy or simply experiencing limitations in normal day-to-day activities, like school or sports. On the other hand, another teenager with Ulcerative Colitis (CU), may suffer from gastrointestinal disorders such as diarrhea, blood in the stools, flatulence or intestinal urgency.

Together, all who have IBD reveal concerns and stress about the crises and the progression of the disease, and/or with medical examinations and treatments, as well as with the impact that IBD has and/or may bring to you and your family in the future. Thus, it seems almost natural that adolescents and young adults with IBD are at an increased risk, in relation to those who do not have IBD, of developing anxiety and/or depression, probably also due to the unpredictable course of the disease.

This link between inflammation and depression/ anxiety even suggests the bidirectional hypothesis that IBD inflammation increases the vulnerability to emotional symptoms and that, by treating these symptoms, we can also help to decrease inflammation, and therefore improve the course of the disease.

Another example of this “storm” is what happens in oral medication, as a component in the treatment. It is essential to initiate and maintain remission of the disease, as well as to prevent future disease flares, in people with IBD.

However, there is a huge and dangerous variability in complying with the medication in adolescents with IBD. In some studies, this lack of adherence to oral medication reaches almost 50%.

And, of course, all of these issues affect and worsen the health-related quality of life of the adolescent, who, fortunately, is not alone. He’s part of a family that also lives with the disease.

I sometimes hear the phrase “being a father is not easy”, and I think that being an adolescent isn’t easy either. Especially, when we have, in addition to IBD, this “storm” inside.

The greater activity of the children’s disease further increases the parents’ perception of uncertainty about IBD. If you were unsure before, then you start to feel really lost. Did you do too much? Too little? Something wrong? What?

And these parents’ uncertainties, in the form of fear or insecurity, may have an influence on the way their children live their own IBD. This can also translate into more intense depressive or anxious symptoms.

And “good parents do everything for their children”, right? Well, the question gets tricky when parents start doing “for their children”. Like, instead of them. As if the disease was theirs in the first place.

It’s very common in IBD, for parents to assume the responsibilities of their children. The parents control the medication, the food, the time of each thing, the exams and medical appointments, the important doubts THEY address the doctor.

Their questions and those that they think are the doubts from the teenager and the kid is right over there, just listening, not participating.

And, of course, they say “if I don’t do it, my son or daughter won’t do anything! He or she has no idea of the severity of his/her illness! He/she’s not a bit careful with his/her own disease!”



*Photo by Toa Heftiba on Unsplash*

Adults with IBD even want their gastroenterologists to ask more questions about their disease, so why not do it with younger ones as well?

Overcoming these barriers to treatment adherence, taking medications, talking more, asking more, without necessarily imposing. Maybe it isn't even necessary to do it. It may not be necessary to impose the medication if the adolescent or young adult with IBD that has to take the medication if he/she understands its importance, thanks to personalized and pedagogical communication. With him or her!

But, when do you think that will change? That your son or daughter with Crohn's or Ulcerative Colitis will start to be aware of the disease if, in reality, at the first impact and for months or years, the parents lived the disease for them? Without leaving them some space. Being ten or a hundred times more afraid of IBD than they are?

Do they have time in the gastroenterologist's appointment to ask their questions? Do they know they can go to the psychologist to talk about their fears?

They may even want to be aware of the disease or at least have a useful contact, in case of doubt or fear, that does not have to go through the parents then what about the privacy of adolescence?

Do you really think your kid will talk freely about what it did, or what it plans to do at that party, or with his girlfriend or her boyfriend, with you listening right next to him/her? I know you tell him/her that he/she can "feel free" to "ask everything", but does he/she really ask "everything"?

When feeling his/her own doubts and fears, wouldn't he/she prefer to spare the parents from it? Especially from all the "blunders" he/she makes behind their backs?

With some irony to the mix, it really should be the easiest thing to imagine. The teenager next to the father or mother asking the doctor if he/she can drink alcohol with that medication, or even how many

"shots" of tequila the intestine can take or even if pain during sex is normal, of course, easy!

And by the way, what about your privacy? Can you put all your parenting questions to the doctor in front of your teenager with IBD? Can you explore all the terrors that have crossed your mind about his/her health with him/her right next to you? Do you cry at ease when he/she is by your side?

Often young adults with IBD have poor skillsets to deal with the disease, largely due to the lack of opportunity to learn it during adolescence. Just because they didn't have to. The parents took care of everything. They had all the doubts, the uncertainties and the panic attacks for them. And not with them.

And at the same time, parents usually feel that they do not know, do not want to, or are simply too afraid to "pass on the testimony".

It's not your fault, nor it's the teenager's fault. But, as much as you feel it too, with all the bad bonuses that it brings with it, the disease is, after all, his (hers).

It's his/her responsibility to learn to take care of himself/herself, and your responsibility to try to teach him/her and be there. Be present. Available without being invasive.

Trust him/her gradually, letting him/her, in a controlled way, to learn from successes and mistakes. Isn't that how you usually do it and did it in your own adolescence?

In your life, and in their illness? Trial and error ... step by step.

Since there is no book or manual to follow, it's parents and teenagers who write it day after day, this adventure book that is IBD in adolescence.

Jorge Ascensão  
APDI – 2019

# WE'RE ON A QUEST TO HEAL

## Discovering a new way forward in IBD treatment

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# Crohn's and Colitis Canada

## Non-medical switch: Biosimilars

Policy changes by governments across Canada to switch patients well-managed on a biologic to a biosimilar for non-medical reasons could affect thousands of Canadians with Crohn's disease and ulcerative colitis.

Governments across Canada are considering a non-medical switch policy that will mandate patients using a certain biologic drug to switch to biosimilar versions. British Columbia Pharmacare has already announced their policy.

We know that for Canadians with Crohn's or colitis, there is nothing more important than achieving and preserving stable remission. In our July 2019 survey, 800 patients and caregivers took the time to explain the arduous, painful and expensive journey they have been on to reach remission.

They expressed true fear and dismay at having someone, who is not their doctor, decide their treatment. New medications to treat Crohn's and colitis are becoming more accessible.

Some of these new medications include biosimilars – biologic drugs that are similar, but not identical, to innovator biologics. Of course, we want doctors and their patients to have access to biosimilars along with existing treatments.

However, some provincial governments are considering switching people on certain biologics to its biosimilar for non-medical reasons, including cost. We took the time to review all available evidence, gather perspectives from patients and caregivers, gastroenterologists and IBD nurses, consult with specialist experts in the treatment of Crohn's and colitis and consider the legal and ethical impact of non-medical switching policy.

CCFA agrees that biosimilars are a safe and effective treatment for people with Crohn's disease and ulcerative colitis but firmly believe that switching from a biologic to its biosimilar for non-medical reasons is not in the best interest of patients.'

For this reason, Crohn's and Colitis has launched a letter-writing campaign asking IBD patients to let their provincial governments know how they feel! CCFA believe that treatment decisions should be made between the patient and the doctor - not by government. Policy change made at the expense of our health is not okay.

For more info: <https://crohnsandcolitis.ca>

## The role of the nurse in the management of chronic inflammatory arthritis

In April 2020 the European League Against Rheumatism (EULAR), has published the 2018 update of the EULAR recommendations for the role of the nurse in the management of chronic inflammatory arthritis.

These recommendations, based upon the most up to date evidence, replace EULAR's 2012 recommendations. A EULAR task force of rheumatologists, health professionals and patients formulated three overarching principles and eight recommendations for the role of nurses in chronic inflammatory arthritis (CIA) care.

The overarching principles emphasise the nurse's role as part of a healthcare team, describe the importance of providing evidence-based care and endorse shared decision-making in the nursing consultation with the patient.

The recommendations cover the contribution of rheumatology nursing in needs-based patient education, satisfaction with care, timely access to care, disease management, efficiency of care, psychosocial support and the promotion of self-management.

The three overarching principles are:

A. Rheumatology nurses are part of a healthcare team. Rheumatology nurses do not work in isolation, but in close collaboration with the patient (and family/ significant others, as appropriate), the rheumatologist and, if applicable, a wider healthcare team, with a common focus on care and outcome.

B. Rheumatology nurses provide evidence-based care. Rheumatology nursing is based on the principles of evidence-based practice. Evidence-based care integrates different sources of knowledge in practice:

(i) research evidence, (ii) clinical nursing experience, (iii) patients' experiences, preferences and values and (iv) the local context. Providing evidence-based care is broader than care based on protocols and guidelines.

C. Rheumatology nursing is based on shared decision-making with the patient. Patients' values and preferences are part of the comprehensive process of proper knowledge exchange and consensus on treatment decision.

The eight recommendations are:

1. Patients should have access to a nurse for needs-based education to improve knowledge of CIA and its management throughout the course of their disease.
2. Patients should have access to nurse consultations in order to enhance satisfaction with care.
3. Patients should have the opportunity of timely access to a nurse for needs-based support; this includes tele-health.
4. Nurses should participate in comprehensive disease management to control disease activity, reduce symptoms and improve patient-preferred outcomes; this leads to cost-effective care.
5. Nurses should address psychosocial issues to reduce patients' symptoms of anxiety and depression.

6. Nurses should support self-management skills to increase patients' self-efficacy.
7. Nurses should have access to and undertake continuous education in the specialty of rheumatology to improve and maintain knowledge and skills.
8. Nurses should be encouraged to undertake extended roles after specialised training and according to national regulations.

In several European countries, rheumatology nursing has developed into a recognised specialty with nurses undertaking both advanced and extended roles. Rheumatology nurses operate telephone advice lines, provide self-management support, patient education and counselling.

Moreover, they participate in disease management, monitor disease-modifying treatments, give intra-articular injections, refer to other health professionals, prescribe drug treatments and help to manage comorbidities.

In some European countries, such as the Netherlands, Denmark, Ireland and the United Kingdom, nurse-led clinics are well established. These add value to patient outcomes and equal the cost of traditional physician-led follow-up.

*Photo by JESHOOOTS.COM on Unsplash*



# About EULAR

The European League against Rheumatism (EULAR) is the European umbrella organisation representing scientific societies, health professional associations and organisations for people with RMDs. EULAR aims to reduce the burden of RMDs on individuals and society and to improve the treatment, prevention and rehabilitation of RMDs.

To this end, EULAR fosters excellence in education and research in the field of rheumatology. It promotes the translation of research advances into daily care and fights for the recognition of the needs of people with RMDs by the EU institutions through advocacy action. More info: [www.eular.org](http://www.eular.org)

## European Medicines Agency

### From lab to patient: journey of a medicine

All medicines must be authorised before they can be marketed and made available to patients. In the European Union (EU), there are two main routes for authorising medicines: a centralised route and a national route.

Under the centralised authorisation procedure, pharmaceutical companies submit a single marketing-authorisation application to the European Medicines Agency (EMA).

This allows the marketing-authorisation holder to market the medicine and make it available to patients and healthcare professionals throughout the EU on the basis of a single marketing authorisation.

However, under EU law EMA has no authority to actually permit marketing in the different EU countries. The European Commission is the authorising body for all centrally authorised product, who takes a legally binding decision based on EMA's recommendation. This decision is issued within 67 days of receipt of EMA's recommendation.

Once granted by the European Commission, the centralised marketing authorisation is valid in all EU Member States as well as in the European Economic Area (EEA) countries Iceland, Liechtenstein and Norway.

Commission decisions are published in the Community Register of medicinal products for human use.

EMA has published an interactive tool that allows viewers to follow the journey of a medicine for human use assessed by EMA. It explains all stages from initial research to patient access, including how EMA supports medicine development, assesses the benefits and risks and monitors the safety of medicines.

Go to tool:  
[www.ema.europa.eu/en/from-lab-to-patient-timeline](http://www.ema.europa.eu/en/from-lab-to-patient-timeline)





# Nutrition and IBD: a strong connection... to understand and develop

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## Background

Chronic inflammatory bowel disease (IBD) is a complex disease that requires not only precise medical attention but also a continuous process of adaptation by patients and their families.

The chronic and progressive nature of the disease also creates a psycho-social discomfort in the patient that often compromises the quality of life in terms of personal, occupational and interpersonal well-being.

In response to such a complex pathology, one issue that scientific literature has recently been focusing on is nutrition and the psycho-social aspects related to it. Although there are still a few studies that investigate the impact of diet on IBD and the IBD patient's quality of life, this issue is starting to arouse a lot of interest.<sup>1,2,3</sup>

## The research

In order to investigate the patients' experience in all its complexity, this research has used the in-depth interview technique.

This technique is aimed at deepening the subjective experience of the person, and to highlight his/her deepest experiences. It is a conversation in which the person is invited to express in a free and profound way his/her representations on a topic.

In this research project EngageMinds HUB conducted 13 in-depth interviews with 13 IBD patients of the Italian IBD patient association AMICI.

The participants were selected to cover the diversity related to:

- gender (male / female)
- age (underage patients 4, young patients and adult patients)
- length of time of diagnosis (old diagnosis vs. recent diagnosis)

In addition, research has also been extended to caregivers, a key figure in the management of nutrition and disease in general when the patient is still very young. 3 parents of underage patients with IBD were also interviewed.

# What's emerged?

Certainly a few pages are not enough to illustrate the depth of the contributions that AMICI members have shared with us. We will therefore try to focus on some main points that we hope will guide health policies in the near future to improve the care of IBD patients.

## 1. The experience of nutrition during the disease and its impact on quality of life

In general, nutrition emerges as a very important element in the management of IBD. Although the gastroenterologist - according to the interviewees - does not seem to be very aware of this, patients and their caregivers seem to be rather worried about it because the control of nutrition is a central and problematic area of intervention to improve the management of IBD.

It is not surprising, therefore, that the emotions of patients and IBD caregivers related to the world of nutrition are very strong; furthermore, they change progressively with the evolution of the disease.

In the early moments of the disease the prevailing emotions related to the theme of nutrition are confusion, difficulty and frustration.

The patient sees food as a “poison” and as an “enemy”: eating, an act until then natural and pleasurable, is the cause of problems and discomfort. It can happen that he/she loses the stimulus and the desire to eat. There may also be a decline in self-esteem due to a momentary inability to self-regulate: the patient feels “belittled” and feels ashamed.

Afterwards, when the situation evolves and improves, a sort of gratitude develops towards food, almost to the point of considering it a “cure” on a similar level to medicines and therapies, because it is only thanks to food that the patient has the energy available for his/her activities, “to do the same things as before the illness” and thus have “a life as normal as possible”.

Nutrition, therefore, takes on great importance for patients: they see it as a powerful ally which, if properly managed, limits the discomfort caused by the disease. Patients often remember when at the beginning of the illness they were unable to eat for many weeks because they saw that “eating everything” aggravated their symptoms even more. Now, their ability to eat in a way that allows them to feel good and have the energy to lead their lives is experienced as a fundamental achievement.

However, there is still the discomfort for the lack of freedom in the choice of food and the nostalgia for the light-heartedness of the before illness (“when you could eat what you wanted”).

The subjective meaning given to “well-being” also evolves as the relationship with food and disease evolves. Immediately after diagnosis, “well-being” basically corresponds to survival, managing pain due to symptoms. In the more evolved and aware phase of the disease, the condition of well-being demands something more: from a physical point of view, to mitigate with some measure - including diet - symptoms otherwise disabling; from an emotional point of view, to regain serenity and hope and the prospect of a positive everyday life in which it is possible to carry out normal activities.

## 2. How the diet changes during the history of the disease

The relationship with food seems to evolve and mature along with the history of the disease.

The disorientation typical of the first moments of the disease also affects the diet, which is managed in a chaotic and unregulated way. In the early stages, indeed, when the patient is still inexperienced and uninformed about the management of the disease, no diet is followed.

It is usually a time when the patient is withdrawn into himself, does not go out, is often unable to work or study and has difficulty in integrating the disease into his/her daily life.

In some cases, patients feel that what they eat may actually have an impact on the IBD course, but they do not yet know how and why, so they experiment “a bit randomly”, by trial and error. Often the absence of a diet has negative effects on health, but also on mood and self-esteem (this is particularly for the caregivers).

The need to make a change in the diet has an important impact on daily life. Nutrition becomes something to organize (shopping, preparing food in advance...): at first with fatigue and with the fear that a mistake will cause an exacerbation of symptoms; then slowly in an increasingly systematic and calm way.

A small minority of patients are those who have struggled most to accept the disease in general; it may happen that they sometimes adopt an oppositional and challenging attitude, a sign of greater suffering, at least temporarily. In some circumstances the desire to challenge and go beyond the limit emerges; to go back to eating everything or almost everything, tolerating the pain caused by the wrong diet.

### 3. Relations with Others

In the initial moments of the disease, inexperience and disorientation lead to a withdrawal into the outside world.

The physical debilitation - also caused by incorrect nutrition, as described above - is accompanied by the feeling that “no one can understand”. It is a moment described as a “black hole” where the patient falls, feeling more and more alone.

Patients' need to focus on their own health, putting themselves and their needs first, would reveal more clearly the nature and value of the relationships experienced so far, acting as a “catalyst”: relationships that are already positive and valuable are strengthened, while those that are more superficial and less significant are seen for what they are and often abandoned.

Respondents talk about a great effort and discomfort in having to explain the characteristics of their illness and the reasons for the dietary restrictions; they prefer to do it only with the most intimate people, being sure to receive understanding and support.

The way to search for information (without falling into the so-called fake news) also matures as the patient becomes more experienced.

In the early stages of the disease, it is not known who to turn to for reliable information or what criteria to use to make decisions about everyday diet.

Only afterwards the patient gets to learn how to find information in a more effective and functional way, gaining satisfaction from the increased ability to manage the disease.

This is mainly due to an important ally: the Patient Association.

### 4. The Patients' Associations

Of all the encounters that patients and their caregivers make, the one with the Patients' Association is undoubtedly the most important and significant. At the Association patients have the opportunity to be listened to, to confront themselves with those who are going through the same experiences, to not feel lonely anymore, but even more to have precious advice on how to manage everyday life, including nutrition.

Indeed, the association seems to meet two basic needs: a) to share the experience of the disease with other peers (i.e. “recognize each other as a group”); b) to receive practical support and personal support in the management of IBD. Both of these supports are important for the construction of one's own personal path of adaptation to nutrition.

“It is impossible to determine by default which food, in what quantity and with what preparation, is good or bad”. It is therefore necessary to experiment in person: with caution, acquiring over time experience and confidence in oneself and one's own management skills. Feeling actively engaged in the management of the disease supports the desire to experiment.

Thanks to the self-confidence they have acquired, patients report feeling free every now and then to allow themselves a “break from the rule”, finding a balance between freedom and responsible management of the risk of symptoms.

## References

1. A. N. Sasson, L. Targownik, K. Vagianos, C. N. Bernstein, A230 Gaps in identifying food-related Quality of life and Hypervigilance in at-risk individuals with IBD: Review of validated screening tools, Journal of the Canadian Association of Gastroenterology, Volume 3, Issue Supplement\_1, 106–107 (2020).
2. L. Guadagnoli, E. A. Mutlu, B. Doerfler, et al. Food-related quality of life in patients with inflammatory bowel disease and irritable bowel syndrome. Qual Life Res 28, 2195–2205 (2019).
3. Cao, Qin, et al. “The prevalence and risk factors of psychological disorders, malnutrition and quality of life in IBD patients.” Scandinavian Journal of Gastroenterology ,1-9(2019).
4. NB: With regard to the interviews conducted with underage patients, it is hereby specified that parental consent has been obtained.

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