

# EFCCA MAGAZINE

European Federation of Crohn's and Ulcerative Colitis Associations

February 2021



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# EFCCA Members

Austria - OMCCV  
www.oemccv.at

Belgium  
CCV: www.ccv.be  
Crohn-RCUH: www.mici.be

Bulgaria - BCUCA  
www.babkuk.org

Croatia - HUCUK  
www.hucuk.hr

Cyprus - CYCCA  
www.cycca.org

Czech Republic - Pacienti IBD  
www.crohn.cz

Denmark - CCF  
www.ccf.dk

Estonia - EPSS  
www.ibd.ee

Finland - CCAFIN  
www.ibd.fi

France - AFA  
www.afa.asso.fr

Germany - DCCV.e.V.  
www.dccv.de

Greece - HELLESCC  
www.crohnhellas.gr

Hungary - MCCBE  
www.mccbe.hu

Iceland - CCU  
www.ccu.is

Ireland - ISCC  
www.iscc.ie

Israel - CCFI  
www.ccfi.co.il

Italy - AMICI  
www.amiciitalia.org

Latvia - LKKSBB  
www.lkksb.lv

Lithuania - CCLA  
www.draugija.info

Luxembourg - ALMC  
www.afa.asso.fr/luxembourg

Malta - MACC  
www.macc.org.mt

Montenegro - CUKUK  
www.cukuk.me

New Zealand  
Crohn's and Colitis  
www.crohnsandcolitis.org.nz

Netherlands - CCUVN  
www.crohn-colitis.nl

Norway - LMF  
www.lmf norge.no

Poland - J-elita  
www.j-elita.org.pl

Portugal - APDI  
www.apdi.org.pt

Romania - ASPIIR  
www.aspiir.ro

Serbia - UKUKS  
www.ukuks.org

Slovakia - SCC  
www.crohnclub.sk

Slovenia - SAIBD  
www.kvcb.si

Spain - ACCU  
www.accuesp.com

Sweden - MOT  
www.magotarm.se

Switzerland - SMCCV  
www.smccv.ch  
www.asmcc.ch

Turkey - IBHDYD  
www.ibhportali.com

UK - Crohn's and Colitis  
www.crohnsandcolitis.org.uk

Associate Members:

Argentina - Mas Vida  
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Brazil - DII Brasil  
www.facebook.com/diibrasil

Kazakhstan - FPVZK  
www.vzk.kz

Trinidad and Tobago - NACCTT  
www.crohnsandcolitistt.org

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# Breaking barriers for a brighter future

What we have seen in recent months is a miracle that has allowed the drug regulatory agencies to approve, albeit in an emergency, a vaccine in just nine months: optimizing and speeding up the economic and bureaucratic part and making the achievement, one of the most beautiful in medical science can boast, which will probably allow us to return to normal, after a period that more than anything, made us appreciate the concept of freedom and the value of affections.

Science works by discussion and consensus building through dialogue and we have discovered how vital scientific research is to improve people's lives and save lives.

The main objectives of patient and family organizations lie in the protection of specific interests related to different health conditions, which range from support to individuals, up to broader advocacy actions such as real prevention and/or awareness campaigns on the disease, on the defense of orphan drugs, guidance on health policies and research.

The role of volunteers' training is strategic to achieve these goals and create a group of people prepared to represent all patients. For this reason, we consider the activities carried out by our Academy to be central.

EFCCA is developing satellite actions around the Academy, such as thematic training workshops, collection and share of best practices, pilot projects. EFCCA will also be available to deliver specific training modules to patient groups to establish an organization, even if it is not IBD related.

What we are doing is building a model that needs to be filled with content. And at this stage, we felt it was essential to develop a clinical trial module.



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volunteers’ training  
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This topic's choice 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.

The aim is to provide participant patients a better understanding of the entire clinical research process and their role in supporting the design and implementation of successful clinical studies.

The dissemination of scientific news plays a fundamental role in assisting and guiding all patients. Given the pandemic and the recommendation to vaccinate against flu, to facilitate the diagnosis of Sars-Cov 2, EFCCA felt the need to clarify the topic of anti-flu vaccines for patients with IBD. We organized a live streaming, with Kawaldip Sehmi (IAPO - International Alliance of Patients' Organisations) and Dr. Bogdan Mateescu (Head of Gastroenterology Department, Colentina Clinical Hospital Bucharest) that talked about actions that patient organizations have taken concerning patient safety and addressed some of the burning questions, raised by the IBD patient community.

Through a social media awareness-raising campaign leading up to 19 May, we want to show the hidden facts about what it is like to live with IBD. Under the hashtag #breakthesilence we want to show the world how a person with IBD feels.

IBD are solitary diseases. To overcome them, we need support, closeness. Trust and rely, therefore, on family and doctors. With the pandemic, we have learned that we must be all united and decide to take the paths we know or trace new ones. A brighter future has just begun.

United We Stand,  
Salvo Leone  
EFCCA Chairman

**“Under the  
hashtag  
#breakthesilence  
we want to show  
the world how a  
person with IBD  
feels”**

Within the framework of our strategic plan, we have annual priority themes, and for 2021 it will be on IBD & Well-being. EFCCA would like to promote the discussion on IBD and wellbeing.

With our World IBD campaign, we aim to start a dialogue and discussions on the disease's psychological impact.



# EFCCA Patient Talk

## Seasonal vaccines and IBD

The hot topic on vaccines, patient safety and medicine availability was discussed amongst patient representatives and invited guest speakers during our latest EFCCA Patient Talk organized on 27 November 2020.

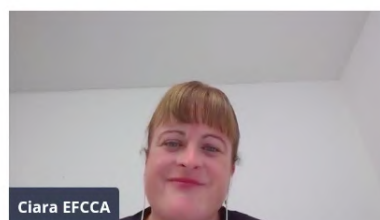
The third webinar which forms part of our EFCCA Patient Talks series took a closer look at the issue of seasonal vaccinations in relation to IBD, patient safety and general awareness around vaccines as well as medicines shortages. The meeting was moderated by Ciara Drohan, EFCCA Vice President and Member of the Irish Crohn's and Colitis Society.

With regard to seasonal vaccines and IBD our invited guest speaker Dr Bogdan Mateescu, Head of Gastroenterology Department at the Colentina Clinical Hospital and Associate Professor at the Carol Davila University of Medicine and Pharmacy (Bucharest) gave an excellent overview around the importance of seasonal vaccinations and highlighted the fact that people with IBD under certain treatment had a significant higher risk of infections for pneumonia or influenza than the general population. Citing a study of Melmed GY, et al: (Am J Gastroenterol 2006;101:1834-1840) amongst the main reason of people in risk groups not being vaccinated was that they simply were not aware that they needed it.

The issue of a lack of awareness or reluctance in participating in vaccination programmes was also addressed by the next speaker, Kawaldip Sehmi from the International Alliance of Patients' Organisations (IAPO) who also gave a general overview of IAPO's work in ensuring patient safety and quality of care for patients.

Another issue that was discussed was around medicines shortages and a lack of availability or difficulty in accessing seasonal vaccines such as the annual flu (influenza) shot.

LIVE 31



### EFCCA Patient Talk: Seasonal vaccines

Our EFCCA Patient Talk will look at the topic of Seasonal vaccines and IBD following a survey that EFCCA had carried out amongst its members concerning the availability and practice of seasonal vaccines during our current pandemic.

## EFCCA Patient Talks

# Seasonal vaccines and IBD

### Free Webinar

Join our discussions on seasonal vaccines and IBD!

Guest speakers include Dr Bogdan Mateescu (Colentina Clinical Hospital, Bucharest) and Kawaldip Sehmi (International Alliance of Patients' Organisations).

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

27 November 2020, 3- 4 PM

A survey that had been carried out amongst members of the EFCCA network prior to the workshop revealed that most countries (62%) experienced shortages such as running out of stock and/or waiting lists for high risk group people.

In the majority of countries IBD was included in the risk group (only if on immunosuppressive treatment) and in which case the influenza vaccines were being covered by the national health system.

You can watch the event on our YouTube channel at: <https://youtu.be/0bE5C3mvmQY>

## EFCCA Academy: Training on Clinical Trials

EFCCA has officially launched the Academy on Clinical Trials offering a new specialized training for patients on understanding the entire clinical research process and the patient's role in supporting the design and implementation of successful clinical studies.

Last November 18th, 2020 the first module called "Clinical trials: basics" of the EFCCA Academy was released via the EFCCA online learning platform. Professors Séverine Vermeire and Marc Ferrante from the Department of Gastroenterology and Hepatology, University Hospitals Leuven / KU Leuven in Belgium opened the training teaching a class entitled "Clinical Trials: the basic information you should know". They explained the different phases in the development of medicines, the revolution in IBD treatment over the years, the efficacy of clinical trials and the safety also in the real-world after drug approval.

Students reacted very positively to this first session and wanted to further investigate the topics by requesting some extra explanations.

We collected around 20 questions and both professors were delighted to go into more details and to see such active participation on the topic.

After having acquired basic information on what clinical trials are and how they work in a therapeutic perspective, the second module released last December 17th, 2020 "Diving deeper into clinical trials", aimed to give students some knowledge of

all the players involved in clinical studies including aspects such as patient education and patients' role within these trials.

Annick de Bruin from the Center for Information and Study on Clinical Research Participation (CISCRP) introduced the module with the class "Clinical Research Overview". Some of the topics covered were: What do we learn from studies? Why is a clinical trial not the same as standard of care? What is the role of the sponsor and the research team? What are the eligibility criteria and how a patient should be trained before participation?

Rob Camp from EURORDIS - Rare Disease Europe, discussed the importance of the patient role in clinical trials as well as patient participation in a Community Advisory Board when it comes to discussing with pharmaceutical companies. During his class on "Patient engagement in research - what is it, why is it important and how can it be done?" he talked about Patient Engagement, Community Advisory Boards - patient organisations engaged with companies regarding trials, Patient education as part of the Community Advisory Board process or as stand-alone (i.e., Train-the-Trainer).

Finally, Ana Sofia Correia - Life Sciences & Medical Translator - ended the module explaining what Patient-Reported Outcomes and Real-World Evidence are, why they are important, how they are collected. She also explained the importance of the Linguistic Validation of PRO measures and the challenges in using them.

Students will have time until January 21st, 2021 to complete the second module and then EFCCA will wrap up the Academy with the final module "Breaking the myths around clinical trials". We already have a valuable list of speakers ready to give their helpful input.

At the end of the course, a final project will be assigned to students in order to validate them as Certified Patient in Clinical Trials.

Maria Stella De Rocchis  
EFCCA European Project Officer



## From the European Union: news on COVID-19 strategy and a brief update on Health4Europe

**CORONAVIRUS:** the European Commission puts forwards rules on rapid antigen tests and secure 20 million tests for Member States

Following up on the Council conclusions of 11 December 2020, the Commission has adopted a proposal for a Council recommendation on a common framework for the use, validation and mutual recognition of rapid antigen tests.

Since the outbreak of the COVID-19 pandemic, diagnostic testing has been rapidly evolving, demonstrating its central role in outbreak control.

The recommendations will ensure the uniform use, validation and recognition of rapid antigen tests in the EU.

The Commission has also signed a framework contract with Abbott and Roche allowing the purchase of over 20 million rapid antigen tests for up to €100 million, financed by the Emergency Support Instrument (ESI\*). From early 2021, these tests will be made available to Member States, as part of the EU strategy to COVID-19 testing.



Stella Kyriakides, Commissioner for Health and Food Safety said: “Rapid antigen tests offer us speed, reliability and quick responses to isolate COVID cases. This is crucial to slow down the spread of the pandemic. Testing will remain fundamental in the coming months, even as we aim to start rolling out our vaccines in the EU from 27 December. We need to scale up testing capacity in parallel to keep the virus under control. To help in these efforts, we have today signed a contract to support Member States with over 20 million rapid tests.”

Concerning the **use of rapid antigen tests**, Member States are recommended to:

- Use rapid antigen tests to further strengthen countries’ overall testing capacity, particularly as testing remains a key pillar in controlling and mitigating the ongoing COVID-19 pandemic;
- Ensure that rapid antigen testing is conducted by trained healthcare personnel or other trained operators where appropriate, and in line with national specifications, and in strict accordance with manufacturer’s instructions and subject to quality control.
- Invest in training and, if appropriate, certification of healthcare personnel and other operators to carry out sampling and testing, thereby ensuring adequate capacities as well as safeguarding the collection of good quality samples.
- Consider in particular the use of rapid antigen tests in the following situations and settings: COVID-19 diagnosis among symptomatic cases, contacts of confirmed cases, outbreak clusters, screening in high-risk areas and closed settings.
- Use rapid antigen tests for population-wide screening in epidemiological situations or areas where the proportion of test positivity is high or very high;
- Ensure that strategies are put in place that clarify when confirmatory testing by RT-PCR or a second rapid antigen test is required,
- Continue to monitor and assess testing needs in line with epidemiological developments.

Concerning the **validation and mutual recognition of rapid antigen tests**, Member States are recommended to:

- Agree on, maintain and share with the Commission a common list of rapid antigen tests that are in line with countries’ testing strategies and appropriate for the situations described above; that carry CE marking, meet the minimum sensitivity and specificity requirements as defined by the Commission and the ECDC, and that have been validated by at least one Member State;
- Agree that this common list of rapid antigen tests is updated on a regular basis, particularly as new results from independent validation studies will become available and new tests will enter the market;
- Agree to mutually recognise the test results of a selection of tests included in this common list;
- Explore the need and possibility for a digital platform to validate the authenticity of COVID-19 test certificates.

*\*Adopted by the Council in April 2020, the Emergency Support Instrument (ESI) allows the EU budget to step in to provide emergency support to allow the Union as a whole to address the human and economic consequences of a crisis such as the ongoing pandemic. The Emergency Support Instrument has already been used for the advance purchase of vaccines and PPE masks earlier this year.*

# EU4HEALTH PROGRAMME 2021-27

## strengthened thanks to a new agreement

In the past issue of our magazine we have been presenting you the EU4Health programme and stressed the fact that the proposed budget allocation was much lower than discussed last spring. However, with a last-minute agreement the German presidency of the Council and the European Parliament reached a provisional deal on the EU4Health programme for 2021-2027. The new reinforced programme of EUR 5.1 billion provides the basis for EU action in the health field based on lessons learned during the COVID-19 pandemic.

The EU4Health programme aims to support the national policies of the member states and to promote coordination between them to improve human health, in particular by:

- supporting health promotion and disease prevention (at least 20% of the budget to be allocated)
- contributing to the protection of people from serious cross-border threats to health
- increasing the use of digital tools and services in the health area, including by contributing to the establishment of a European Health Data Space

- increasing cross-border cooperation, i.e. by European Reference Networks
- supporting global commitments and health initiatives by international organisations, in particular the World Health Organization (WHO)

The programme will also address long-term public health issues such as the prevention and treatment of communicable and non-communicable diseases, notably cancer, as well as the improvement of mental health and the reduction of health inequalities.

The provisional agreement is now being ratified by the EU Parliament and member states' permanent representatives but is expected to be implemented from January 2021.

Finally, please check the link:

[www.consilium.europa.eu/en/policies/coronavirus/10-things-against-covid-19](http://www.consilium.europa.eu/en/policies/coronavirus/10-things-against-covid-19) you will find an interesting set of information about the 10 things the European Union is doing to fight COVID-19 and ensure recovery.

Luisa Avedano  
EFCCA CEO



# World IBD Day 2021

World IBD Day takes place on 19 May each year and unites people worldwide in their fight against Crohn's disease and ulcerative colitis, known as inflammatory bowel diseases

This year and within the framework of our EFCCA strategy plan we will be focusing our activities on the theme of IBD & Well-being.

EFCCA would like to promote the discussion on how the disease affects you not only physically but also emotional and psychologically. What are the masks that you are wearing on a daily basis? How do you REALLY feel?

We believe that people living with IBD often do not tell their real story. They might live with pain and think it's just part of the disease. They might feel bad about their self-image but do not talk about it. They might have good medical scores related to their disease, but their quality of life is not good.

With our World IBD campaign we aim to start a dialogue and discussions on the psychological impact of the disease. Through a social media awareness raising campaign leading up to 19 May we want to show the hidden facts about what it is like to live with IBD. Under the hashtag #breakthesilence we want to show the world how a person with IBD really feels.

During the second stage of the campaign - following the discussions - we would like to take the main issues raised to Health Care Providers and other stakeholders for them to listen and to find solutions that will have a meaningful impact on a person's quality of life.

More details will follow soon on our web. We hope you can join our campaign!!!



**WORLD IBD DAY  
19 MAY**

## IBD and Well-being

#breakthesilence

#worldibdday2021



# Drug shortages affecting IBD patients

Several EFCCA members have reported a lack of availability of certain IBD medications in their countries. This has become even more accentuated during the current pandemic

On 13 November 2020 EFCCA was invited to participate in a meeting organised by Pr Ferrante (Leuven IBD Center), the Green Party General Secretary Vula Tsetsti and the French MEP Michèle Rivasi.

The meeting focused on the drug shortage for IBD patients since the situation started to become serious in many countries during the COVID-19 crisis, especially in Belgium.

As EFCCA already organized a patient talk in July to underline this important issue and to raise awareness about medicines shortage during the COVID-19 crisis, we gave our availability to collect information on this subject from all our members.

Mid-November, EFCCA sent out the invitation to all the members, asking to share with us information about the medicine's shortage for IBD patients during the COVID-19 crisis.

As results of this call, most of the responding countries reported that Salazopyrin (500mg tablet) from Pfizer Company was not available. Other countries reported the lack of Questran 4gr powder and Prednisolon tablet as well.

However, some countries such as Finland and Poland did not have any problem with drug shortage.

This first meeting was an opportunity for EFCCA to become more visible, thanks to the collaboration with MEP Rivasi and the Greens and a way of lobbying the EU health agenda.

We will continue to focus our efforts on this important issue and to bring these matters to the responsible policy makers.

More info about our webinar on COVID-19 and medicines supply: "Are we running out of medicines?" [www.efcca.org/en/events/efcca-patient-talk-no1](http://www.efcca.org/en/events/efcca-patient-talk-no1)

Veronica Pisco,  
Project Assistant

**“Drug shortages have a harmful impact not only on the physical but also on the mental health of patients. More efforts and coordination is needed from relevant officials to address this complex issue”**

# Poland

## 15th Anniversary of our association

For 15 years, the Polish Association Supporting People with IBD “J-elita” has been educating, integrating and supporting people suffering from Inflammatory Bowel Diseases.

When 15 years ago a handful of Polish patients with IBD and parents of sick children got together to help each other, exchange information and fight for access to modern treatment, none of them dreamt that they would achieve so much together.

Today, “J-elita” Association is the largest patient organization supporting people with IBD in Poland. It has almost 3000 members and local chapters in 14 out of our 16 regions. Its members include parents of sick children, patients with IBD, as well as a gastrologist/professor and a pharmacist (MD). Thanks to this, and thanks to the cooperation with the medical and scientific community, “J-elita” is so effective.

“Our actions: appeals and expert opinions have led the Ministry of Health to introduce three new biological drugs in recent years” says the president of “J-elita” Agnieszka Gołębiowska, mother of two daughters with Crohn’s Disease.

Since 2007, “J-elita” has been continuously publishing the Quarterly Magazine “Kwartalnik J-elita”, which is sent to our members, to gastroenterology clinics and hospitals managing IBD patients. Currently it has a circulation of 4500 copies.

“Education and sharing knowledge about the disease, how to cope with its symptoms in everyday life and methods of treatment, is one of the most important elements of our mission” emphasizes President Gołębiowska. “That is why all our publications and guidelines are free, they can also be downloaded from the website.”



In 2020, a new edition of the “Guideline for adolescents and parents of children suffering from Ulcerative Colitis and Crohn’s Disease” was published.

Face-to-face meetings are the best opportunity for conveying knowledge, sharing experience and integration. This is the main goal of Seminars about IBD, which “J-elita” has organized for patients and their relatives in the largest cities in Poland for twelve years. In 2020, due to the pandemic, the lectures were held online and thus reached a larger audience. The lecturers included the best specialists in Ulcerative Colitis and Crohn’s Disease in Poland, and part of the lectures was devoted to COVID-19.

“J-elita” is the only organization in Poland that offers rehabilitation camps for children and adult IBD patients. Summer camps are organized at the seaside and winter camps in the mountains. In 2019 alone, 300 people participated in them. We hope to be able to meet again in 2021.

Jacek Hołub  
“J-elita” Association





# Pioneering for patients

We don't think it is good enough that countless people affected by fibrotic and inflammatory conditions are still living with debilitating symptoms. That is why we are determined to change this. We are relentlessly searching for medicines to tackle the progression of the disease itself. We are driven by thinking about the positive impact this could have, not only in changing the lives of those affected, but also on their families, friends and societies in general.

[Discover more at glpg.com](https://www.glp.com)

**Galápagos**  
Pioneering for patients



# France

## World Toilet Day - 19 November A Day Essential for the IBD Cause

Alongside World IBD Day on 19 May, 6 months later World Toilet Day seems to us just as essential to raise public awareness on IBD.

This day puts the spotlight on an alarming state: 2.5 billion people in the world do not have access to toilets and 2 million children die every year from diseases due in large part to a lack of sanitation and hygiene. But this is not only a problem in the Southern countries. In France, it is also difficult to mobilize policy makers on this issue, which is too often taboo, and our toilets are reputed to be “exotic”. Since the Palace of Versailles of our King Louis XIV and his “cabinets” behind the curtain drapes, we haven’t changed much!

Afa has been mobilized for more than 15 years on this issue and has called on elected politicians to open public toilets free of charge in many cities. The political statement is: The accessibility of toilets is thus a real issue in maintaining social life and fighting against the isolation and withdrawal of the IBD patient. Madeleine Duboé, former delegate of afa to EFCCA, brilliantly pleaded this cause and was one of the first to have the toilets modernized and created, free for everyone, in her beautiful town of Pau in the Southwest of France with the signing of a convention with the city hall, the merchants and the hotel, restaurant and café businesses.

We managed to set up a Carte Urgence Toilettes (Emergency Toilet Card) recognized in many cafés and restaurants, and then set up a dedicated application that geolocates the toilets that are private partners of IBD and public toilets. Finally, since 2019, we founded a partnership with BeTomorrow, a company who manages the Toilet Finder application in France and who is gradually extending this application to all of Europe and the rest of the world.

### Text of our petition:

More than ever, at this time of a health crisis, it is important to give access to toilets and promote hygiene throughout the population. However, we note that this access to toilets is far from obvious in our country: few public toilets (many have even been closed with the lockdown), and few toilets in transportation: this poses a real problem, in particular for the chronically ill, such as Crohn’s disease and ulcerative colitis patients whom we represent, but also for people with other disabilities, the elderly, but also pregnant women and families. In short, everyone is concerned.

The issue of toilets at school is also problematic: many toilets in schools are outdated or insufficient in number. But there is also the question of anything to do with toilets being taboo and the lack of privacy. It is estimated that 66% of the children refrain from going to the toilets at school.

This has an impact on their physical health (urinary tract infection, abdominal pain) and mental health, stress in particular, and from there an impact on schooling, that is on concentration in class. Therefore, there is an urgent need for an information campaign with parents, teachers, and children, of course, to break this taboo.

For several years now, awareness-raising campaigns on invisible disabilities have been organized in schools, using the example of IBD and taking the opportunity to raise the issue of toilets.

At the beginning of November 2020, we launched a petition that was widely spread by other associations concerned (the elderly, parents, other diseases, etc.)

to call on our political representatives on the need, in France, to make access to toilets a public health priority.

This action can therefore be taken in all European countries, because what will serve our fellow citizens, will serve all IBD patients!



## New Zealand

### I Can't Wait Campaign Launch

In January 2017 12-year-old Nicole Thornton petitioned Parliament, seeking access to workplace toilets for people with medical conditions when no public toilet was available. Nicole has Crohn's disease. Like the more than 20,000 New Zealanders with Inflammatory Bowel Disease (IBD), diarrhoea and urgency are frequent symptoms.

Compounding all their medical challenges, fear of having an accident in public can be a major concern of people with IBD. When the need arises, those with Crohn's disease and ulcerative colitis often do not have time to explain their personal medical histories to a stranger and many business owners are unaware of the challenges they face. While CCNZ offers "I Can't Wait Cards" identifying those with documented medical conditions where urgent access to a toilet might be needed, many businesses still will not honour the card. As a result, many people are simply afraid to leave home.

Nicole's petition went to a Health Select Committee where she bravely presented testimony. Unfortunately, a bill mandating that businesses provide toilet access to those with medical problems was not recommended.





Instead, the committee strongly recommended publicising the “I Can’t Wait” card and “encouraging business owners to allow toilet access via an education campaign”. On 9 December, Crohn’s and Colitis New Zealand, the Lower Hutt City Council and the Hutt Valley Chamber of Commerce, jointly launched a nation-wide campaign for toilet access.

Merchants were asked to prominently display a sticker in their window that they honour the CCNZ “I Can’t Wait Card”. The event took place at the Atrium Café in Lower Hutt and received extensive media coverage. CCNZ Ambassador Nicole, CCNZ Chair Richard Stein, Lower Hutt Mayor Campbell Barry, and Chamber of Commerce CEO Helen Down spoke at the event. Numerous business throughout the city are already displaying the stickers.

The campaign will be going into full swing after the New Year. Three other city councils have already approached CCNZ to promote the stickers.

Our goal is to have stickers in businesses in every city and town throughout the country so people with IBD and other medical problems will feel free to leave home without worry.

Both the stickers and the “I Can’t Wait” cards are available at no cost.

Dr Richard Stein,  
Chair







# WE'RE ON A QUEST TO HEAL

## Discovering a new way forward in IBD treatment

Roche GastroImmunology is exploring unique molecules to redefine outcomes for patients who need it most. To us, altering the course of IBD is more than a goal – it's our mission.



GastroImmunology™



# Italy

## AMICI Young - The Youth Group is born

“A group of people who share a common purpose can reach the impossible”. The spirit that leads AMICI Young can be explained with this little quote.

Three years ago, AMICI Onlus developed an ambitious and revolutionary project related to pediatrics: the “Summer Camp Junior”, a camp dedicated to youths suffering from IBD. On that occasion, some young patients met for the very first time and after knowing each other, they started teaming up. In only seven days together, they became friends not only because they faced the same challenges related to the disease, but also because of their everyday life.

The project was very successful and for this reason, in 2019 we decided to repeat it but this time, eight young women and men aged between 16 and 18 went to Lanzarote, a small isle in the Canary Island, to attend the Lanzarote Summer Camp.

Again, the test was successful and the bond between the kids was so strong and special that one year later they were pushed to meet again but online because of a global pandemic. In fact, it has been since March 2020 that these kids every week go online with the intention to tear down physical distances, cultivate their friendship and make their dreams come true.



I have known them since the beginning, and I can say that the Summer Camp has changed deeply the way they live their disease. In fact, the response they had was the need to create a network to reach as many young people as possible.

What characterizes this group is the strength that you can gain with this kind of relational exchange where individuals can feel welcomed and understood.



AMICI  
YOUNG

They chose the name “AMICI Young” to identify themselves inside a national and complex reality as is the National Association AMICI Onlus, where patient’s needs are always in the foreground.

As a volunteer of the Summer Camp, I followed from the very beginning the evolution and the growth of the kids: Adriana, Davide, Filippo, Emily, Giuseppe, Lisa, Marco, Silvia and Sofia. They have the light and the energy of those who want to commit and dedicate themselves to a real and close reality for the ones who are still struggling to find their place.

When I attend their meetings as supervisor I notice their breakthroughs and their decisions and I realize that the association invested in them without expecting anything in return and unexpectedly, we are reaping the benefits of what I expect to be the future of the volunteering and of our association.

Genuine, spontaneous and full of contradictions, they let you advise them without losing heart. I think that this is the antidote which gives you the push to keep working even when you feel the fatigue.

You need a lot of energy to follow them in this journey because their enthusiasm is so strong, but the satisfaction of achieving the objectives pays off.

To the kids of the group, I feel like saying that there is nothing more beautiful than doing something good together for the others and I wish you not to exhaust the strength that led you so far. To those who are reading the article, I only suggest trusting them; usually, what is made with the heart, never disappoints.

Noemi Fiumanò  
AMICI Onlus Volunteer

## Brazil

# DII Brasil trains young patients for nationwide leadership actions

The National Association of Patients with Inflammatory Bowel Diseases, DII Brasil, develops works to target patients with Crohn’s disease and ulcerative colitis in all age groups.

Last year, patients Lorena Eltz, from Rio Grande do Sul, and Lara Carolina, from São Paulo, came together within a project of DII Brasil to bring DII Jovem to life (DII = Inflammatory Bowel Diseases Jovem = Youth)

It was their second time together, since 2016, when they met to record their stories and spread the word regarding Inflammatory Bowel Diseases to young people. At that time, both were under 18.

Now they are joined by young people from other Brazilian states. Through social networks and in a Telegram group, they keep in touch with patients between 18 and 25 years old. The project is sponsored by Barbara Monteiro, Miss Brazil Plus Size.

Besides Lorena and Lara we also have involved in the actions: Luciane Lachouski and Letícia Lachouski, from Paraná; Nicollas Emerick, from Rio de Janeiro; Carolina Almeida and Cora Sanches, from Minas Gerais; Gabriela Hoeppers, from Santa Catarina; Luan Soares, from Rio Grande do Sul; Pedro César, from Roraima; Sara Tavares, from Maranhão; and Tayná Antunes, from Espírito Santo.

The work is developed by each of them according to their competencies in their respective areas of study. Everyone also participates in management courses with the DII Brasil Executive Board so that they are increasingly prepared as leaders.



With the endorsement of the Nacional board, DII Jovem team holds monthly meetings attended by members of the Scientific Council and the Legal Committee of DII Brasil in order to provide information of interest to the cause to young people.

Regarding patients under 18, the team is developing the DII Teens project, with a format adapted to this age group.

DII Jovem team invites all young people to interact and exchange information, whether in Latin America or Europe. You are all welcome!!!



## Netherlands

### My boss is purple!

With purple trophies and short films, in which five people with IBD tell about the impact of their illness on their (volunteer) work, Crohn & Colitis NL drew a lot of attention to IBD & work on social media, in the first week of October 2020. We put work in the spotlight that week, as a follow-up to previous campaigns during World IBD Day on May 19, 2020.

What could be more fun than surprising your boss with a purple trophy to express your appreciation for the way he/she deals with your illness? 70 people with Crohn's or ulcerative colitis responded to our call to put their boss in the spotlight by handing over the My

Boss is Purple Trophy. A number of people shared the handover on social media. In addition to the trophy, some bosses also received flowers, cake or cupcakes.





Henk, lecturer at Windesheim University of Applied Sciences, was diagnosed with ulcerative colitis twelve years ago.

He has always been very open about his illness with his supervisor and colleagues. Starting work later, flexible working hours, working from home and dealing smoothly with hospital visits have never been a problem. That's why Henk's team leader Frank received the purple trophy from Henk.

Willemijn is a junior HR advisor at Actium Housing Corporation. She had a severe flare-up of Crohn's disease in August 2019, which prevented her from working for a longer period of time. The many examinations and hospital visits were never a problem for her employer. "I've been given all the space and help to recover."

### **Five films about IBD and (volunteer) work**

Crohn & Colitis NL also shared five films about the impact of IBD on (volunteer) work in the same week. Miranda talks about her colleagues who stayed in touch while she was recovering from her surgery at home. Cynric had the dream of becoming a Chemistry teacher, but things turned out differently. For years, Aylin unsuccessfully tried to adapt her work to her illness. Rob kept his international career going thanks to always going to bed early, eating healthily, and practicing sports regularly. And Jeanine found her calling in her volunteer work. All films can be viewed via: [www.crohn-colitis.nl/actueel/werk-en-ibd-stand-week-spotlight](http://www.crohn-colitis.nl/actueel/werk-en-ibd-stand-week-spotlight)

### **Other activities**

Crohn & Colitis NL sent checklists for employees with IBD and their employers to IBD-nurses in every Dutch hospital. These checklists provide tips and answers to the most frequently asked questions about work and IBD. All health and safety services in the Netherlands also received these checklists, as well as the factsheet with results and advice from our research into working with IBD. The checklists and factsheets can be downloaded from our website.



# Slovakia

## #SmeMedziVami

The Slovak Crohn Club has launched a new campaign under hashtag #SmeMedziVami (being amongst you) aimed to raise awareness and to start an open dialogue about what it is like to live with Inflammatory Bowel Diseases.

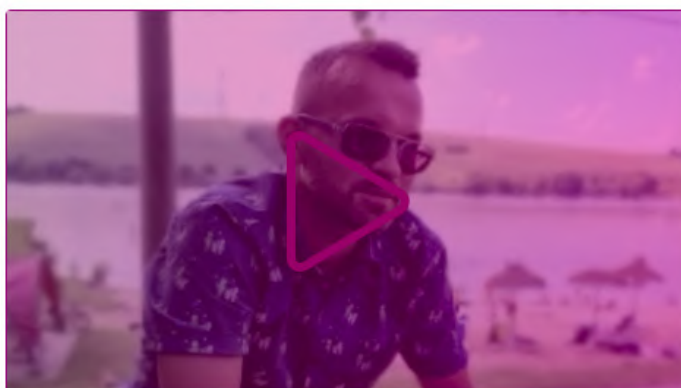
We want to share our everyday struggle with IBD but also share our achievements and life objectives. Throughout the campaign we will collect 10 IBD patient stories with various symptoms and different grade of severity.

The campaign will also disseminate information and articles about IBD written by IBD specialists.

We hope you can join our campaign and help us raise awareness!

For more information please visit:  
[www.crohnclub.sk/kampan-sme-medzi-vami](http://www.crohnclub.sk/kampan-sme-medzi-vami)

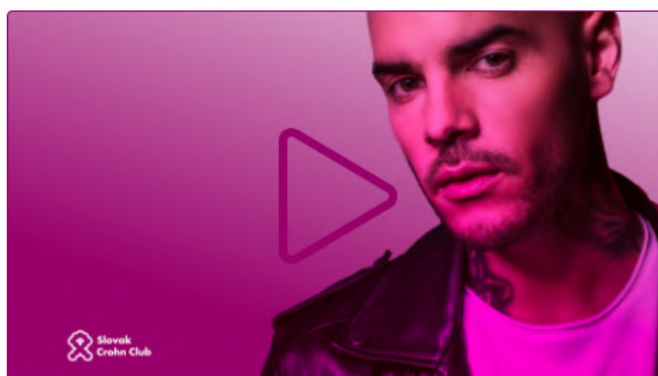
Veronika Ivančíková,  
 President SCC



### The story of Rasta

Rasto has had Crohn's disease for 12 years. In his story, he will show you how this disease affected his life in the past and how it affects him today. Listen to him!

[Play video](#)



### Majself: People get a lot of signs to make a change, and it's important to listen to those signs

Hear what Majself's beginnings were before the diagnosis of Crohn's disease and what prompted him to change his lifestyle.

[Play video](#)





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# Crohn's and Colitis Australia

## Expressive Writing Intervention for IBD patients to cope with COVID-19 stress

Do you have IBD (Crohn's disease, ulcerative colitis or indeterminate colitis)? Are you worried about the recent COVID-19 pandemic?

Researchers at Australia's Deakin University are seeking people who would like to test an online writing intervention aiming to reduce worry associated with the COVID-19 pandemic. If you have IBD (Crohn's disease, ulcerative colitis or indeterminate colitis), are 18 years of age or older, worry about the COVID-19 pandemic, and have access to the internet, you are eligible to participate.

However, please note the study is only addressed to people with mild to moderate levels of distress as this intervention is not suitable for people with severe distress.

The findings from this study will provide data on the usefulness of a simple online intervention for people with IBD.

To express interest or if you have any further questions about this research:

[www.crohnsandcolitis.com.au/research/clinical-trials/current-research](http://www.crohnsandcolitis.com.au/research/clinical-trials/current-research)



**Expressive Writing  
Intervention for IBD Patients  
to Cope with COVID-19  
Distress**

Do you have IBD and are you worried about the COVID-19 pandemic?

We are seeking people who would like to test an online writing intervention aiming to reduce worry associated with the COVID-19 pandemic.

To express interest or if you have further questions, please contact the study email [writeforibd@deakin.edu.au](mailto:writeforibd@deakin.edu.au)

This study has received Deakin University Ethics approval: 2020-122



# EAHP Opinion on COVID-19 Vaccine Programmes and their Implementation

In December 2020, the European Association of Hospital Pharmacists (EAHP) issued an Opinion on COVID-19 Vaccine Programmes and their Implementation. The opinion touches on challenges posed by the distribution of COVID-19 vaccines and their administration.

EAHP draws attention to transport and storage conditions, underlines the importance of good logistic processes and record-keeping and shares information that could help with combatting vaccine hesitancy.

Since not all hospital pharmacies, especially those operating in small hospitals, are equipped with cooling facilities that can meet the conditions needed for some of the COVID-19 vaccines, EAHP called on national authorities to consider the local storage conditions in their national vaccination programmes to ensure a smooth roll-out of the vaccination activities across the healthcare sector.

Linked to the administration and record-keeping the importance of tracking which person receives which vaccine and which dose of the vaccine was highlighted and the setting up and utilisation of a database was suggested to support the vaccination process and the pharmacovigilance activities of hospital pharmacists.

Attention was drawn to the role of hospital pharmacists, who as part of the vaccination team, are committed to raise awareness and to share clear information with citizens.

EAHP encourages national competent authorities to set up national vaccination awareness programmes for the COVID-19 vaccines which involve the expertise of healthcare professionals as trusted sources of information.

Read the EAHP Opinion on COVID-19 Vaccine Programmes and their Implementation [HERE](#)

## Portuguese EU Presidency

On 1 January 2021, Portugal took over the Presidency from Germany. The members of the current Presidency trio - Germany, Portugal and Slovenia - will continue to work closely together to achieve the goals set out in its [joint 18-month programme](#)

The Portuguese Presidency recognises the importance of combatting the current public health crisis and strengthening the EU's preparedness and crisis management, while also boosting research and innovation and reaping the benefits of digital transformation in the health sector.

Its major health-related targets during the presidency include to reinforce EU ability to cope with public health crises, European Health Data Space (see article below) and increased digital health skills.

Further priorities include navigating an ecological transition to more environmentally sustainable practices and driving digital transformation across justice, social security and health services, with a “Charter of Digital Rights” being proposed to enshrine trust in the digital economy.

Safety and health at work will feature prominently during Portugal’s term.

Visit the [website of the Portuguese EU Presidency](#)



*Joint Press Conference of the Minister for Health, Marta Temido, and Commissioner for Health and Food safety, Stella Kyriakides*

## European Health Data Space

The creation of a European Data Space is one of the priorities of the European Commission 2019-2025, including the health sector. A common European Health Data Space will promote better exchange and access to different types of health data (electronic health records, genomics data, data from patient registries etc.), not only to support healthcare delivery (so-called primary use of data) but also for health research and health policy making purposes (so-called secondary use of data).

The entire data system will be built on transparent foundations that fully protect citizens’ data and reinforce the portability of their health data, as stated in article 20 of the General Data Protection Regulation (GDPR). The Commission, in collaboration with the Member States, is engaged in the preparatory work

and development of the European Health Data Space. Member States will be supported by a new “Joint Action for the European Health Data Space” set up to help the Member States and the Commission facilitate the sharing of health data for public health, treatment, research and innovation in Europe.

The European Health Data Space will be built on 3 main pillars:

- a strong system of data governance and rules for data exchange
- data quality
- strong infrastructure and interoperability

## Governance of the European Health Data Space

Preparatory work was conducted in 2020, through a series of workshops and a study to provide a framework for the primary and secondary use of health data in the Member States, particularly through

- a mapping of how the GDPR is implemented in the health sector in the different countries, including an overview of the legal and technical modalities applicable to health data sharing for primary and for secondary uses in the EU countries
- an overview of the existing governance structures for secondary use of health data in the EU countries
- recommendations for possible actions, legislative and non-legislative, at EU level to facilitate health data sharing across the EU for primary and for secondary uses

## Data quality and interoperability

To fully exploit the potential of exchanging health data, it is essential to ensure health data quality and that the various sources of health data (e.g. electronic health records, different registries, various IT or digital tools) are able to “talk” to each other. This requires technical and semantic interoperability between the different infrastructures and IT systems.

It is also important to ensure that the health data are findable, accessible, interoperable and reusable (FAIR). The Commission is supporting mapping and “FAIRification” of existing health data registries and other data sources to establish common data sets for exchanges for health research and policy making purposes.

## Infrastructure and technology

The infrastructure at European level will follow the overarching strategy of the European Data Space launched by the publication of the European strategy for data on 19 February 2020, while at the same time providing in-depth analysis of health sector specificities.

It will build on and potentially scale up existing initiatives such as the eHealth Digital Service Infrastructure, the European Reference Networks and the Genomics project.



# Real Talk About Fistulae

**By Tina Aswani Omprakash**

This article from blogger Tina Aswani Omprakash talks in an open and honest way about what it is like to live with fistulae. It might be at times an uncomfortable read but it is important to understand the impact fistulae can have on the quality of life of a person with IBD. For more information about Tina's blog "Own Your Crohn's" please visit: [www.ownyourcrohns.com](http://www.ownyourcrohns.com)

To find out more about a survey EFCCA has been undertaking on the impact of fistulae please visit: [www.efcca.org/en/projects/impact-perianal-fistulae-crohn's-disease-patient's-quality-life](http://www.efcca.org/en/projects/impact-perianal-fistulae-crohn's-disease-patient's-quality-life)

As I sit here today with a very heavy heart typing out this blog post, I'm not sure if the excruciatingly painful nodule I felt earlier this week is just another health scare or yet another horrifying abscess from a fistula. I hold back tears as I wonder what my next steps are and what I can do to keep spiraling anxiety in check.

Now many of you might be wondering what I'm even referring to-abscess? Fistula? What the heck are those and why am I such a mess over them? Well, get ready for some real talk about the most harrowing experience I've faced as a Crohn's patient.

According to InflammatoryBowelDisease.net, "an abscess is a collection of pus."<sup>1</sup> Abscesses related to Crohn's fistulae often form when the intestines become so inflamed that the mucosal wall begins to break down to cause an infection. A fistula forms when the intestinal barrier ruptures and creates a tract into another organ or out on to the skin. Some common examples of fistulae run from the intestines to the bladder or anus, and others run from the rectum to the genitals, causing significant pain, distress, sepsis and morbidity.

So, how does having an abscess and fistula affect me? This is where things get deeply personal and become incredibly difficult to write about and share. So here goes nothing...

In my 13 years since diagnosis, I've had 5 rectovaginal abscesses that became full-fledged fistulizing tracts.

Additionally, I developed a massive honeycomb-shaped abscess in my pelvis from which, yet another fistula was headed for my tailbone. I was told that this fistula could have paralyzed me if it broke through my skin. And I needed surgery immediately... lots of it.

And I needed very strong doses of medication to prevent my immune system from continuing to lay its siege on my intestines.

You see, living with a fistula, let alone 6 of them, isn't just a humbling experience; it is a back-breaking, jaw-dropping, mind-numbing experience that ripped me apart from the inside out. The thing people often don't realize is that fistulae violate our beings right at the seat of our womanhood, threatening our basic identity as human beings. And that, in and of itself, is paralyzing.

To think I could have one yet again isn't just mortifying; it legitimately makes this disease a monster that feeds off my entire being from my sense of self to my self-worth and everything in between. And to rebuild myself after fistulizing disease rearing its ugly head has been one of my most daunting and arduous efforts to date.

As if all this isn't bad enough, I'm in the midst of the new-year woes of transitioning from one insurance policy to another. Even though my surgeon wants an MRI stat, I'm still awaiting confirmation that my new insurance is in effect. And once my insurance is active, I need a prior authorization to get the MRI.

As I wait through the holiday weekend to get some clarity, my anxiety ebbs and flows while I hope and pray that I don't end up in the ER.

So, why am I telling you all such a deeply personal story today? Not to martyr myself and certainly not to aggrandize my experience with this disease. I write this blog post to educate the masses on an immensely stigmatized topic that goes unheard and unrepresented. Because it isn't sexy or attractive to have a fistula or abscess. Because if having a "bathroom disease" isn't hard enough, living with a draining fistula is that much more shameful and dehumanizing.

It doesn't matter what kind of fistula one has (obstetric, Crohn's or otherwise). The reality is that fistulae ruin lives and they wreak havoc on our physical AND mental health. And they need to be addressed for purposes of education and improvement in quality of life and emotional health. Even though fistulae sometimes close with medication or can be surgically repaired, oftentimes, they reopen and remain a chronic source of infection. And in their wake, they leave behind a trauma so real and so deep that it feels impossible to heal ourselves and move forward.

According to the Worldwide Fistula Fund, approximately 1 million women around the world live with some type of fistula.<sup>2</sup>

Take that number in for just a second. 1 million. And the fact of the matter is discussion around fistulae is still extremely limited and stigmatized across all cultures and societies. Even while navigating the medical world as a Crohn's patient, the subject feels taboo and off limits. By way of example, many of us often struggle to talk about menstruation even though it is a natural bodily process. So, can you imagine the shame involved in discussing the unnatural process of a body that is constantly attacking and betraying us?

But I challenge this notion. I challenge the stigmas around fistulae. Why does this have to be a shunned topic? Why can't we talk about fistulae to help others cope and not feel ostracized? In my mind, discussion can only liberate those suffering in silence for the sake of mental health. As I sit here pondering all these questions, I try my level hardest not to panic about this nodule, which may or may not be an abscess.



I sit here wondering if this will need surgery and if my chemotherapy and immunosuppression is cutting it to keep the abscesses/fistulae at bay. I sit here waiting for what feels like an eternity, bringing my mind back to all the beauty that life has to offer in spite of living for years with raging disease. And I keep reminding myself that I dealt with 6 of these before and survived, so if this is my 7th, I will not go down without a fight.

Crohn's might ravage my body, but it can't take away my spirit. It can't take away my will to survive and thrive in the face of the most violating of health circumstances. So, I sit here today practicing what I preach: to own my Crohn's, own my fistulae, and own whatever that MRI may bring because I will be ready to embrace it and fight like hell the way I always have.

Love, light & peace always

1. [www.inflammatoryboweldisease.net/symptoms/complications/abscess](http://www.inflammatoryboweldisease.net/symptoms/complications/abscess)
2. [www.worldwidefistulafund.org/what-is-fistula/fistula-stats.aspx](http://www.worldwidefistulafund.org/what-is-fistula/fistula-stats.aspx)

# COVID-19 vaccinations in patients with inflammatory bowel disease

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Advances in the treatment of patients with inflammatory bowel disease (IBD) have substantially improved disease activity and quality of life, and reduced hospitalisation rates and the need for surgery. However, prolonged immunosuppression in these patients can result in increased susceptibility to opportunistic infections. Many of these infections are preventable through vaccination and immunisation strategies that should be undertaken as early as possible after diagnosis, because the risk of opportunistic infections increases following the first year of immunosuppressive therapy.<sup>1</sup>

The COVID-19 pandemic has led to substantial concerns for patients with IBD who are on immunosuppressive medications, many of whom are using additional protective measures. Although early COVID-19 studies have suggested that immunosuppressive medications are safe, robust and reproducible data are not available to adequately risk stratify patients with IBD, and current measures are mostly based on observational studies and theoretical risk.<sup>2</sup> Large scale, prospective, population-based registry studies and meta-analyses have identified key risk factors associated with

a higher probability of mortality from COVID-19, including age, socioeconomic deprivation, diabetes, respiratory disease, obesity, and being from a Black, Asian, or other minority ethnic group.<sup>3</sup>

One of the best ways to mitigate against the risk of COVID-19 is the rapid development of safe and effective vaccines. Although initial phase 1/2 studies are promising,<sup>4</sup> patients on immunosuppressant medications have largely been excluded from these studies, creating potential future concerns regarding safety and generalisability of outcomes for individuals with IBD.

To achieve a sufficient degree of herd immunity, vaccination programmes are primarily successful only when there are high rates of coverage and acceptance. The importance of patients with IBD being included in vaccine trials is compounded by the concern that these patients have a lower response to vaccinations and that vaccinations are generally underused in this population. Melmed and colleagues<sup>5</sup> showed that in patients with IBD there was an uptake of only 22-46% for the influenza vaccination, and a mere 9% were vaccinated for pneumococcal

pneumonia, despite both vaccines being recommended in the British and European IBD guidelines for vaccinating patients.<sup>6</sup>

A patient survey showed a perceived lack of benefit from vaccination as the most frequent reason for low vaccine uptake, as well as concerns regarding side-effects, risk of disease flares, needle aversion, and inconvenience.<sup>7</sup> However, in the present pandemic, both perception of risk and health awareness might be very different, with implications for vaccine acceptance.

In patients with IBD who were vaccinated against influenza, an immune response was induced, but use of concomitant infliximab and immunomodulatory therapy were associated with inadequate rates of seroconversion.<sup>8</sup> In adult populations vaccinated with the pneumococcal vaccine PSV-23, an impaired immune response was shown in patients with Crohn's disease taking combination immunosuppressive therapy.<sup>1</sup> Other vaccines such as those against hepatitis A and B virus, tetanus, and herpes zoster have also been shown to be potentially less effective in patients with IBD than in control groups.<sup>9</sup>



The extent to which medications might affect vaccine response, independent of underlying disease activity, is unclear. Of note, concurrent anaemia, which is a common finding in patients with active IBD, might impair response to vaccinations.<sup>9</sup> There is therefore an urgent need for better understanding of both the effectiveness of potential vaccines against severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) in patients with underlying health conditions, as well as the potential impact of effective disease control on rates of vaccine response. Currently, the candidate vaccines in phase 3 trials include inactivated, mRNA, or vector-based approaches. The classic inactivated or live attenuated vaccines raise safety concerns due to possible induction

of the disease. However, the ChAdOx1 nCoV-19 trial vaccine uses a replication deficient chimpanzee adenovirus to deliver a SARS-CoV-2 protein to induce a protective immune response. This vaccine seems to be promising for patients with IBD because adenovirus vectors do not integrate the viral genomic DNA into the host's genome, are highly immunogenic, and can induce robust innate and adaptive immune responses. The same adenovirus vaccine platform is also being assessed for use against malaria, HIV, influenza, and Ebola virus.<sup>10</sup> Nevertheless, the phase 1/2 trials of the ChAdOx1 nCoV-19 vaccine were done on young, healthy volunteers and as such do not address the potential immunity concerns in patients with chronic diseases or

those on immunosuppressants.<sup>4</sup> Moreover, we cannot assume that data on one vaccine type in a specific group of people can be extrapolated to other vaccine types.

There needs to be a stronger emphasis on vaccinating patients with IBD within the broader health-care preventative scheme. It is important that these factors are considered when policy makers and national health services start to design and develop future COVID-19 vaccination programmes. Equitable access to COVID-19 vaccination programmes should be endorsed. If this is not feasible, then we propose that future community vaccination programmes support and promote vaccines that can be used by the high-risk cohort of patients with IBD.

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