

## **EFCCA DRAFT WORKPLAN 2021**

This plan was presented at the EFCCA General Assembly that took place online last 29 May, 2021.

The plan is based on the 2021 EFCCA provisional budget which is based on contracts already signed with numerous stakeholders and multiannual grants.

It is grounded in the EFCCA Strategic Plan 2019-2022 and will be developed around the thematic area **IBD and life-cycle**.

The Strategy Plan has been drafted by EFCCA Executive Board and Secretariat taking into consideration needs and priorities of its members and the IBD patient community as a whole. Its main objective is to nourish the 4 strategic areas in which EFCCA's past and current activities have been structured: Networking, Awareness Raising, Advocacy and Empowerment, and it is the framework in which the annual work plans will be developed setting out objectives, activities and outputs to be achieved each year.

**IBD & Life cycle** will prioritise on discrimination due to IBD in youngsters/seniors, IBD in the family and IBD and maternity

Regarding **networking and** taking into consideration the dramatic growth EFCCA has experienced all over the globe, the main focus of this year will be to strengthen relationships among all its members and delivering tailor-made services based on the needs and requests from the patient associations. Different health systems, unequal access to health services and care as well as cultural differences will be addressed.

Medical societies and policy makers will be targeted with the purpose of getting more involved in the EFCCA activities and claims.

The newly introduced activity aiming at reinforcing connections with members and among them is the EFCCA Happy Hour.

 <p>EFCCA WE ARE DELIGHTED TO INVITE YOU TO THE EFCCA HAPPY HOUR!! LET'S MEET UP AND SHARE IDEAS! <b>HAPPY</b> APRIL 23 FROM 5PM TO 6PM APRIL 30 FROM 5PM TO 6PM MAY 5 FROM 5PM TO 6PM <b>HOUR</b></p>	<p>The voice of our members at the centre: brainstorming for new ideas, projects, joint initiatives. Different topics presented by the EFCCA Board and by members: New training models for the Academy Paediatric IBD Youth Academy Council of Advocates</p>
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After the huge success of the pilot experience the EFCCA HAPPY HOUR becomes a regular appointment.

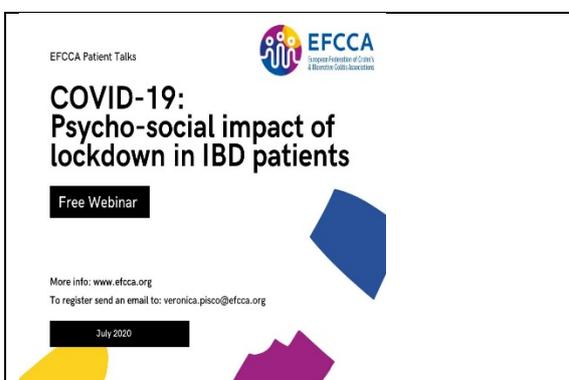
Regarding our **awareness raising** activities the plan will be structured on the outcomes of the 2021 World IBD Campaign in which we want to start a dialogue and discussions on the psychological impact of the disease, to show the hidden facts about what it is like to live with IBD. Under the hashtag **#breakthesilence** we want to show the world how a person with IBD really feels.

IBD is a life-long disease and we will voice out our Community's rights by claiming them in front of policy makers and every stakeholder at EU and global level who is interested in supporting our cause. We will be working to organise an in-person event in Brussels, or, if not possible we will hold it online.

A common thread links our **awareness-raising** and advocacy activities.

The results of the surveys we have worked on over the last two years, such as the one of Perianal Fistula and the one on the impact of COVID 19, allow us to process information and data that become the backbone and content of our EFCCA Patient Talks.

The EFCCA Patient Talks are one-hour online events where internationally renowned experts present a topic, or different positions on the same topic, and then answer questions from our members. They are educational and informative activities and have been remarkably successful. The list of topics below is not exhaustive and a full calendar will be provided shortly.

 <p>EFCCA Patient Talks <b>COVID-19: Psycho-social impact of lockdown in IBD patients</b> Free Webinar More info: <a href="http://www.efcca.org">www.efcca.org</a> To register send an email to: <a href="mailto:veronica.pisco@efcca.org">veronica.pisco@efcca.org</a> July 2020</p>	<p>Key speakers and patients' conversations on</p> <ul style="list-style-type: none"> <li>- CPAF survey</li> <li>- Project IBD Family first</li> <li>- Young people and IBD</li> <li>- Seniors and IBD</li> <li>- Telemedicine</li> <li>- Back to "normality"</li> </ul>
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The EFCCA ACADEMY is the flagship of our **empowerment** activities.

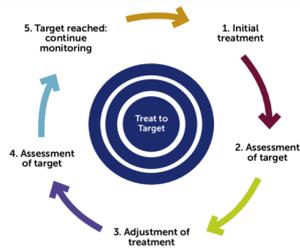
Its main purpose is to train patient experts that can then transfer their know-how and skills at national level and be able to train other patient in their countries.

Over the past 15 months EFCCA has invested a substantial amount of resources in responding to the unprecedented situation caused by the pandemic.

All lessons have gone online, and a new, more powerful platform has been launched.

The Academy has thus become a true online university: with lessons, tests and exams implemented online.

 The logo for EFCCA academy features a stylized blue and yellow graduation cap icon to the left of the text 'EFCCA' in blue and 'academy' in a larger, bold blue font.	<p>Academy year 2021-2022</p> <ul style="list-style-type: none"><li>• CLINICAL TRIALS second round</li><li>• LEADERS FOR TOMORROW - YOUTH ACADEMY</li><li>• PATIENT PREFERENCES</li></ul>
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**2021:** literature review, identification of the main issues and launch of the campaign; tailor-made techniques of involvement and inclusion

**2022:** interim report of the outcomes and involvement of medical societies and relevant stakeholders. From unmet needs to possible solutions

**2023:** publication of the results and global event to raise awareness and claim for changes.

### **The patient preferences and unmet needs project is the newborn activity**

After a literature review phase, a campaign to collect data on patient preferences and unmet needs under the current pandemic will be launched in the second semester of 2021. The focus will be to identify patient unmet needs and preferences regarding their treatments, with a special focus on quality of life and quality of care. We believe that patients should be given the best possible treatment options not only in quality of care but also quality of life allowing them to live their life to the fullest. Data collection will be based on a previous work we have carried out assessing the impact of IBD on a personal social, work, and intimate life. The project will involve the global EFCCA network (45 members) and will allow us to obtain data to prepare targeted actions and identify policy decision making protocols.

The treat to target (T2T) approach will be also included in this empowerment initiative with the purpose of getting a stronger insight through direct input from patients that will be involved in a process of inclusion and empowerment.

It will be a multi-annual activity involving a multi stakeholdership whose different achievements will be presented stepwise.