EFCCA STRATEGY PLAN 2019-2022
Anti-Discrimination Action
About EFCCA

The European Federation of Crohn’s & Ulcerative Colitis Associations (EFCCA) is an umbrella organisation representing 36 national Crohn’s and Ulcerative Colitis (collectively known as IBD) patient associations.

We are an organisation of people united in our commitment to improve the life of over 10 million people living with IBD worldwide (3.4 million in Europe alone), to give them a louder voice and more visibility.

Contact Details

Rue des Chartreux 33-35
B-1000 Brussels Belgium
Tel/Fax: +32 2 540 8434
Registraion: 1096/97
Revised 22/2/2006
No. 459814543

Chairman:
Salvo Leone
Salvo.leone@efcca.org

Honorary Secretary and Vice President: Ciara Drohan
clara.drohan@efcca.org

Treasurer:
Marko Perovic
marko.perovic@efcca.org

CEO: Luisa Avedano
Tel: +32 483 371 194
luisa.avedano@efcca.org

Deputy Director:
Isabella Haaf
Tel: +34 606 849 937
bella.haaf@efcca.org

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Background

This Strategy Plan for the period of 2019-2022 provides direction to our member associations and informs stakeholders of EFCCA’s Vision, Mission, Values and the Priority areas EFCCA intends to focus on in the coming four years and how it plans to implement them.

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.

Thanks to the commitment of all its members, the Board and the Secretariat EFCCA has grown significantly and has achieved high visibility among a wide audience. It has become the reference point for many different stakeholders, including healthcare providers, the academic/scientific world, other patient organisations and the pharmaceutical industry. EFCCA has already developed a number of relevant and important projects, widely known in the IBD community. The data gathered, developed outcomes and evidence-based materials represent a solid and reliable set of resources that constitute the backbone of our journey as the soundest IBD patient community worldwide.

This Strategy Plan lays its foundations in previous work and successes and it is based on available resources. The 2019-2022 Strategy Plan will 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.

Over the course of the next four years, EFCCA will monitor, evaluate and inform on the implementation of this strategy following a set of indicators and measures agreed during its design.

Discrimination

The cross-cutting goal of the 2019–2022 EFCCA strategy is to tackle discrimination, since discrimination, in its various forms, including impeded or limited exercise of rights and access to services, emerged to be one of the most significant burden on IBD patients.

Discrimination is not a new topic to EFCCA. It was already introduced at the High-Level Conference “From EU Citizenship to IBD-zenship”, held at the European Parliament in October 2013. On that occasion EFCCA members, Members of the European Parliament and representatives of the European Commission focused the debate on 3 themes: Employment and Labour Market, Research, Young People and Education highlighting unequal access to them that the IBD patient community experienced and still is experiencing both at national and international level. Furthermore, the outcomes of the two International Symposia on Research supported and funded by patient organisations which EFCCA organised (2012 and 2018), clearly show the importance of voicing patients’ unmet need and priorities when it comes to research to shed light to forms of discrimination faced by people with IBD in Europe.
In particular, the need of better liaising social aspects, such as inclusion, equality in accessing care, better recognition of specific needs for specific disease areas clearly emerged and gave us the inspiration for supporting the launch of new projects such as the Mapping on Innovative Medicines and Devices, the survey on indirect costs on IBD, just to mention the most recent.

The findings of EFCCA’s previous major projects contribute to strengthening the relevance of the anti-discrimination cross-cutting goal. The IMPACT survey (2010-2011 on almost 5000 IBD patients) showed that 1/5 of respondents had felt discriminated at their workplace due to IBD; the BAB survey (2014-2015 on over a 1000 IBD patients) showed that patients lack high quality information leading to worries and concerns. BAB’s outcomes clearly pointed out that patients need to be more involved in the decision-making process concerning their treatment.

The Mapping project, (2016-2017), mapped out access to various innovative treatments in EFCCA’s member countries and showed notable differences between, even within countries e.g. being able to choose the health care provider, accessing treatments, payment schemes, etc.

All three projects highlighted how IBD patients are discriminated in different settings and contexts, such as discrimination at work, unequal or inadequate access to health care or health information and lack of involvement in decision-making. Within discrimination four priority areas have been identified with the purpose of better tailoring EFCCA activities:

1. IBD & Quality of care
2. IBD & Work
3. IBD & Well-being
4. IBD & Life cycle

Each of these priorities will be plugged into EFCCA four strategic areas of intervention which constitute the backbone of the Strategy Plan and are aligned with our vison and mission: Networking, Awareness Raising, Advocacy and Empowerment. EFCCA will address one priority area per year.

We have re-designed our Vision, Mission and Values. Our values have been redefined through a brainstorming activity of the board members and secretariat, in order to reflect the principles and EFCCA’s ethical approach to the whole global IBD patient community.
EFCCA’s Vision, Mission and Values

Our vision is to find a cure for IBD. As no cure has yet been found, the members strongly believe that our vision remains to find the cure for IBD.

Our mission is to improve the overall well-being of people affected by Crohn’s Disease and Colitis, collectively referred to as Inflammatory Bowel Disease (IBD). The word “well-being” is replacing the word “life” used in the previous mission, as it better reflects EFCCA’s work.

Both Crohn’s disease and Colitis are placed in the mission sentence. “Ulcerative” is left out to make sure the mission also covers other forms of colitis, e.g. undefined colitis. Instead of “people with IBD” the members decided to refer to “people affected by IBD” as this covers also e.g. patients’ families and friends.

Our values are based on our tagline “United We Stand” and are as following:

**PEOPLE:** We believe that people are the focus of our efforts. We believe people make EFCCA and people are our greatest resource.

**UNITY:** We are a community aiming at improving well-being of people with IBD and we believe that together we work better towards our mission and to support, learn and share with each other.

**INTEGRITY:** We have strong principles of ethics, honesty, transparency and expect high ethical standards also from our partners. We will always follow through on our commitments and demonstrate the highest standards of personal and organisational behaviour.

**COMMITMENT:** We are dedicated to make a valuable contribution to the well-being of people affected by IBD by fostering engagement, involvement, activism and to ultimately find a cure for IBD.
Strategic and priority areas

EFCCA will pursue its Vision and Mission by focusing on one priority area per year cross-cutting every strategic area.

The four **Strategic Areas** to achieve our mission are as follows:

1. Networking
2. Awareness Raising
3. Advocacy
4. Empowerment

In order to tackle the cross-cutting goal of overcoming discrimination within the IBD patient community, the four Strategic Areas of intervention will cover Priority Areas, one per each year of this Strategy Plan implementation.

The **Strategic areas** embody the overall scenario in which EFCCA has been working and will work. They characterise its identity as an international umbrella organisation and support its role, mission and vision. As explained below, networking, awareness raising, advocacy and empowerment can be considered the logical framework through which the activities and initiatives included in the Priority Areas will be carried out.

For instance, the Priority Area “**IBD & Quality of Care**” that will nourish EFCCA 2019 workplan will contribute to reinforce the Networking Strategic Area by involving members and stakeholders, will offer new or revised evidence on awareness raising, will give new elements for meaningful advocacy projects and support our community in its challenging pathway towards full empowerment.

Finally, the four Priority Areas listed below have to be seen as part of an overall set of actions that not necessarily come to an end the same year they are launched, but as components of a virtual circle whose final objective is to tackle discrimination against people with IBD, anti-discrimination being the cross-cutting goal of this Strategic Plan.

The four Priority Areas that have been identified are:

1. **IBD & Quality of care** will prioritise on discrimination in accessing adequate care, doctor-patient communication and relationship, personalised medicine.

2. **IBD & Work** will prioritise on discrimination in the labour market and at the workplace, labour rights, social policies and disability policies

3. **IBD & Well-being** will prioritise on discrimination based on stigma and taboos focusing on intimate relationships, social exclusion and mental well-being

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

These Priority Areas will nourish the 2019-2022 Strategy Plan. These Priorities will be plugged into the four EFCCA Strategic Areas.

In practice, projects like the EFCCA Academy, whose training themes will be included in the workplans, will provide content for the priority areas and, in the meantime, contribute in reinforcing the logical framework of the Strategic areas.
Networking

EFCCA encourages and facilitates collaboration, exchange of information, knowledge and practices, and the promotion of international activities. We strive to collaborate with different stakeholders to establish and strengthen relationships in order to build a stronger IBD community.

Representing a relatively small disease group, it is vital that EFCCA develops and strengthens synergies and partnerships that are beneficial for all. EFCCA has a high reputation worldwide among a range of stakeholders and it encourages, facilitates the exchange of information and the promotion of international activities.

It collaborates with European institutions, other umbrella associations such as Health Care Professional organizations like the European Crohn's and Colitis Organisation (ECCO) representing the IBD medical professionals, N-ECCO representing IBD nurses, the United European Gastroenterologists Federation (UEGF), the European Society for Paediatric Gastroenterology Hepatology and Nutrition (ESPGHAN), and the Medical Nutrition International Industry (MNI); umbrella patients’ associations, such as the European Patients’ Forum (EPF), the International Alliance of Patient Organisations (IAPO), industry organizations, such as the European Federation of Pharmaceutical Industries and Associations (EFPIA), EuropaBio, and many other networks and organisations working on health.

EFCCA will continue and strengthen its active engagement with other strategic partners, such as organisations representing other immune modulated diseases or other chronic diseases in line with the European Commission and WHO recommendations. EFCCA will improve its collaboration with WHO, ILO, OECD and other relevant global institutions, pursue positive relationships with members, partners and stakeholders. This is to foster mutual benefit to sustain members that want and can influence European and national institutions through EFCCA. Given the spontaneous and natural development of EFCCA beyond the EU borders, EFCCA is now at a tip point. EFCCA has partners and strong collaborations with IBD sister organisations all over the world and will continue exploring ways to evolve into a global federation.

EFCCA will reinforce its partnership with stakeholders also through the organisation of a joint conference with relevant medical societies, the consolidation of further scientific collaborations through the establishment of a permanent scientific committee and a more structured alliance with other immune-mediated disease areas.

Awareness-raising

EFCCA will continue to raise awareness about IBD as there is still little public understanding of the pain and chronic suffering with which IBD patients courageously cope with every day of their lives. Through various initiatives, education and tackling taboos and stigmas around IBD, we want to have IBD accepted and recognized, taking into consideration the needs of all those who are affected.
World IBD Day remains EFCCA’s most powerful tool to raise awareness around IBD. In 2018, EFCCA united 50 countries from 5 continents to participate on World IBD Day. More will be done to better coordinate the work around the World IBD Day, such as its recognition by WHO, additional activities to support member organisations, and a common theme for all participants. EFCCA aims to seek continued support from medical societies to have a stronger commitment in supporting its awareness raising campaigns.

EFCCA participates in high level, scientific and evidence-based research and will push for patients’ priorities, such as biosimilars. EFCCA will continue to use relevant tools, such as the International Symposia on research. EFCCA will continue to explore new topics, such as patient safety and correct information on biosimilars.

EFCCA will foster its facilitator role, will collect inspiring practices and encourage innovative models of care promoting IBD Care Centres of excellence and establishing an online Observatory on research developments to become an international reference point for researchers and potential funders. EFCCA magazine, website and social media tools will disseminate its activities and plans and give visibility and support to members and partners worldwide.

Advocacy

EFCCA carries out advocacy work with EU institutions and international organisations such as WHO to move from a therapy-focused approach to a more patient/person-focused approach, ensuring that concerns, needs and priorities of people living with IBD are included in the decision-making process for policies and other related health initiatives.

Advocacy is one of the most challenging aspects of the life of a second level organisation as EFCCA is. A stronger investment in the area of Advocacy is foreseen by, strengthening and widening EFCCA advocacy efforts. European Policies on social inclusion, as well as diverse levels of recognition of disability rights have been already identified as relevant advocacy topics. A comprehensive analysis of the current state of the art will be the starting point for future actions.

Findings from EFCCA’s latest surveys (e.g. IMPACT and BAB) show that medical professionals are not cooperating enough with IBD patients and their associations. EFCCA carries out institutional advocacy to influence decision-making by generating evidence and ensuring that patients’ concerns are included in the decision-making process for policies and other related health initiatives. Future EFCCA advocacy action will aim at promoting patient-focused policies and improving quality of care; ensuring that the rights of people living with IBD are better integrated in all EU policy areas, especially equal access to labour market, education, and equal access to health care; ensuring EFCCA remains eligible for EMA, the European Medicine Agency, consultations when the patients’ opinion regarding medicines and devices used by people with IBD is needed; exploiting previous surveys (e.g. IMPACT, BAB, and the Mapping survey) to develop advocacy materials and tools; finding ways to support weaker or more discriminating countries, through policy recommendations, policy papers, educational activities, joint guidelines with medical societies, tool-kits to support members at national level.

The European Parliament resulting from the next round of European elections in May 2019, will be targeted. Newly elected MEPs and the longest serving ones will be approached to organise an EU event by 2020.
Empowerment

EFCCA supports its members in their work and mission at national level through the exchange of best practise and capacity building activities such as educational seminars, thematic workshops, policy initiatives and helping to establish new associations in countries where they do not yet exist. EFCCA wants to invest in creating sustainable resources, training independent, self-confident patients and in increasing the collaboration with members.

The most recent European lobbying activities on antidiscrimination in education and in the labour market saw leaders and representatives of the EFCCA Youth Group in the front line. EFCCA will continue to support the Youth Group ensuring its full inclusion in the Federation overall strategy and regulations, as young people represent EFCCA’s asset being the leaders of tomorrow. Efforts will be made towards the re-launch of EFCCA international summer camps and offer a friendly, educational and inclusive environment addressed to youngsters. EFCCA will invest more resources in the EFCCA Academy, as its major tool to empower IBD patients. Certified patients’ role will be of paramount importance to support educational activities at national level and reinforce the sense of belonging of members.

Around the Academy, EFCCA will develop satellite actions, such as thematic training workshops, collection and share of best practices, pilot projects such as Patient Voice whose objective is to put patients and patient organisations as first and unique reference point on data collection and data ownership. EFCCA will also be available to deliver specific training modules to patient groups aiming to establish an organisation, even if such organisation is not IBD related.

Thematic training workshops in individual countries are envisaged to share best practices and support mutual learning. Members will continue to be informed on latest news and innovations on IBD treatments through proper communication tools.

Moving forward

In four years’ time, EFCCA aims to reach visible changes in national and international policies for people affected by IBD; a bigger and more effective network with all relevant stakeholders, more joint projects with its members; a more comprehensive overview of good practices and successful activities developed by members and sister organisations and achieve a stronger, prouder and inclusive IBD community.

The results of IMPACT, BAB and Mapping of Innovative Medicines surveys will nourish and support EFCCA activities in combination with ongoing projects such as identifying and highlighting the societal costs and impact of IBD. Further activities and projects will follow the direction given by this Strategy Plan and will contribute to its implementation. EFCCA sustainability and financial strategy, its communication plan as well as its daily management are and will be driving forces of the Federation and the Board. The Secretariat will assure that resources (human and financial) and assets will be employed in the most effective and profitable way to transform the 2019-2022 Strategy Plan into a concrete set of activities and projects towards its final and ultimate objective: finding the cure for people with IBD.

Transparency in any activity is vital and always important for EFCCA. Members are therefore welcome to enquire at any time how the work is progressing.